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PREVENTING AND CARING FOR LOW BIRTH WEIGHT AND DEVELOPMENTAL DISABLED BABIES

HEARING

BEFORE THE

SUBCOMMITTEE ON FEDERAL SPENDING,
BUDGET, AND ACCOUNTING

OF THE

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GOVERNMENTAL AFFAIRS
UNITED STATES SENATE

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PREVENTING AND CARING FOR LOW BIRTH WEIGHT AND DEVELOPMENTAL DISABLED BABIES

SATURDAY, MARCH 21, 1987

U.S. Senate,
Subcommittee on Federal Spending,
Budget, and Accounting,
Committee on Governmental Affairs,
Tampa, FL.

The subcommittee met, pursuant to notice, at 9:30 a.m., at the Howard Johnson Plaza Hotel-West, Hon. Lawton Chiles (chairman of the subcommittee) presiding.

OPENING STATEMENT OF SENATOR CHILES

Senator **Chiles**. Good morning. Mark Twain once said, "Among the three or four million cradles now rocking in the land are some which this Nation would preserve for ages as sacred things, if we can know which ones they are."

The truth is we never know which one of the millions of babies born in our world every day will end up as a future president or statesman or religious leader, innovative engineer or pioneering doctor or precedent-setting judge. But as a nation, we value each of those lives as being tremendously important and want to save each one of them, that way we know that we'll save the future president or judge or anyone else.

We have the obligation and we are justified in trying to make sure that every child born in this life has a healthy start and an opportunity to have that healthy life.

Unfortunately, that's just not happening. For the fourth consecutive year, the progress of the United States in reducing overall infant mortality has slowed, placing us now twentieth among the industrialized nations in infant mortality.

Despite dramatic technological advances, America is still behind countries such as Singapore, Australia, Hong Kong, and most of Western Europe. There is just no reason for this. It's a national shame.

In Florida, 1,120 children are added to the population every day. Of those 1,120 children, 12 will become infant mortality statistics. They will die before their first birthday.

Damage to the unborn and newborns can occur for different reasons: Little or no prenatal care, drugs, alcohol, smoking, poor nutrition, genetic abnormalities, stress, and maternal age.

The main cause of infant mortality, however, is low birth weight. Some 6.7 are under five and a half pounds. Those that are lucky enough to survive their first day often spend many days and months and even years with costly or burdensome handicaps.

Teenagers, poor women, and non-white women are most likely to have low birth weight infants. Black infants are twice as likely to have a low birth weight and die before their first birthdays as babies born to whites. Teenagers are twice as likely to have their offspring die before their first birthday than babies born to older women.

Women most likely to have low weight babies are also most likely to have inadequate prenatal care.

A recent survey done in 1984 found that for the fifth consective year, there was no progress in reducing the percentage of infants born to women who received late or no prenatal care. And Florida is, unfortunately, one of the ten worst states for women receiving late or no prenatal care.

Low birth weight babies are 40 times more likely to die in the first 28 days of their life, 20 times more likely to die in the first year, if they are not treated.

If all women had early or regular prenatal care, Florida's low birth weight births could be reduced from 75 per thousand births to at least 30 per thousand.

The March of Dimes has found that two percent of women who receive early ongoing care have low birth weight babies, as opposed to nine percent change for those who do not.

Too many children are meeting untimely deaths and enduring preventable handicaps. Too many parents and families are suffering that devastating loss of a newly born baby or are experiencing lifelong agony of raising a disabled child.

By 1990 the annual bill for the first year of life will total $2.1 billion, while the cost of providing sufficient prenatal care would only be $500 million. That's a startling number, $2.1 billion as opposed to $500 million. To do that we're also talking about erasing the agony, of all those who would suffer in the future.

I guess, again, it was Will Rogers who said that "The happiest time in a politician's life is when conscience and convenience could cross." If there is a place where it should cross, it should be in trying to do something about this statistic, to try to put that money out there in the early years. That is, again, part of our task to convince every county commissioner, every State legislator, every national legislator this is something, if we intervene early, can make a tremendous savings.

Last year we passed legislation granting states the option of expanding Medicaid coverage to pregnant women and children, zero to five above the Aid to Families with Dependent Children cutoff and below the federal poverty line. In his budget, I'm delighted to see that Governor Martinez has included monies for pregnant women and children from birth until age two. That certainly is a good start.

This is a problem that we can solve. It's an embarrassment to us as a nation, to each of us as leaders of the country that we have not been able to do better on this now. But a life no matter how new or how young is too wonderful a thing to squander.

Today we're going to hear from a number of different people. We are going to hear from parents who have suffered the tragedy of low birth weight or disabled babies. We are going to hear from providers, people who are attempting to solve these problems and make available the services necessary to care for the disabled children. And finally, we are going to hear from Speaker Jon Mills who has committed the Florida House of Representatives to dealing meaningfully with this problems.

The hearing will help provide the evidence and the background for the development of a coherent national policy on this issue.

I think we have to be innovative. I think we also have to be quick. Many federal programs can be creatively combined with State funds to improve the access to prenatal and infant health care. Medicaid has been expanded, and as we will hear later, community organizations and even business ventures are beginning to develop new methods for providing much needed services.

As some of you know, one of my grandchildren, who happens to bear my name as the 4th was born very premature. For many weeks, I watched his struggle and I watched the struggle his parents went through in trying to deal with that problem, and to have to leave him behind in the prenatal care facility at Gainesville. We are very fortunate, he survived and today is a normal, active five-year-old. Howèver, because of adequate prenatal screening which now is improved, his mother has just delivered a third infant, a normal full-term child.

I realize that for far too many the outcome is not always that good. This is a problem for which there is a solution. In many instances we can prevent the low birth weight babies. And, when they do occur we can make the necessary development services immediately available for the parents.

Last year I introduced legislation creating a National Commission on Infant Mortality. The Commission is going to attempt to provide a comprehensive gameplan which we need to coordinate the federal and state policies and services that effect access to prenatal care. It's going to address the gaps in our service delivery and reimbursement systems, and more importantly we hope it will help to heighten public awareness and force a national consensus on this issue.

It's not a study Commission. We really don't need to study this any longer. We need to see how we can mobilize the troops and bring our resources to bear.

I look forward to hearing from each of our witnesses and I extend an invitation to all of you here today to write me of your experiences or explaining your experiences. We'll then make them a part of our record and available to other members of Congress on this issue.

We are delighted today that Dick Batchelor is going to be our first witness. Dick is a former legislator that I had a pleasure of serving with at one time and has a distinguished record as a member of the State legislature. He has worked on health and related matters, people issues all the time that he was in the legislature. He is now chairperson of the Prevention Task Force and vice chair of the Governor's Constituency of Children.

Dick, we're delighted to have you here and we'll ask you to present your statement. I read your statement in full, we'll put it in the record. If you wish to brief it in some way, we'll have time for questioning, and we'll be delighted to have you do that.

TESTIMONY OF DICK BATCHELOR, CHAIR, PREVENTION TASK FORCE AND VICE CHAIR, GOVERNOR'S CONSTITUENCY OF CHILDREN [1]

Mr. BATCHELOR. Thank you very much, Senator. Let me, if I might, make a personal observation and I won't recall the year, but I recall when I was of the young Democrats and you as a State sneator, I had the pleasure of working with and decided to walk across the State, and I was very impressed but only impressed enough to walk all the way across Orange County on Highway 17-92 with him. That was some years ago and it was really gratifying to have a friend, personal friend and a friend of children sitting as chairman of the Senate Budget Committee.

The last time I testified to Senator Chiles' Committee it was on the other end of the age spectrum and that was the Senate Aging Committee when I was chairing the House Senate Aging Committee in the Florida Legislature at the age of 29, but it gave me an opportunity to tell Floyd Pepper that I had beat him to the chairmanship by 50 years. So it's always a pleasure to see you.

Senator CHILES. The problem is he's getting younger and you and I are not.

Mr. BATCHELOR. That's an astute observation, thank you. I also want to point out that Speaker Jon Mills is here early. He's been very generous with his time today even though he has a full schedule, not only is he testifying but he's here to hear the testimony that will be presented to you, Senator, primarily by the parents. I think that's a great signature in support of the Speaker of the House of Representatives when he's willing to do that and have it firsthand from the parties.

Senator CHILES. We're delighted to have Speaker Mills here. We know that he has had a long advocacy and career in helping people work out their problems. We're delighted to have him here.

Mr. BATCHELOR. I might say the last comment before I make my formal comment is that when you lobby a legislator, having been one for eight years, you have to be creative sometimes. And I met with Jon yesterday and he was extremely receptive as always on children's issues, but I learned this morning that I could have saved myself and him some time because his neighbor DJ from Gainesville is here, and she said if you just deliver banana bread to his house, he's usually very receptive. So DJ you will be on call for the remaining parts of the legislative session. If we can't find him, we can sure find the banana bread for you to deliver.

Senator, I'll get to my remarks and I'll try to abbreviate them. First of all, we want to thank you for being here with us again. It is very, very important when the Senate Budget Committee Chairman joins to take testimony from parents who are so effected by policy or lack of policy.

I want to share with you briefly some of the Prevention Task Force findings, some of the things that we found in the State, I will hasten to add that the Prevention Task Force was appointed by the Secretary of HRS and we are funded by the Developmental Disabilities Planning Council of which we are an arm.

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[1] See p. 43 for Mr. Batchelor's prepared statement.

We were charged with developing an action plan to primarily find ways to reduce the infant mortality rate in this State to prevent developmental disabilities and minimize the effects of disabilities. We studied State plans, federal plans, we looked at programs that were successful not only in the State of Florida but throughout the Nation.

We held 11 hearings around the State. We heard testimony or at least we had participation from some two thousand parents in those 11 hearings that we had around the State.

It was heartening to find that our first meeting in Fort Myers we had 250 people in attendance and frankly we did not even have standing room, which served as impetus for us to go back and be even more assertive about the advocacy.

I was shocked to find that the facts we found in the State, the number of children who were born and do not live until their first birthday, and also equally shocked to find that we have so many children who are born with handicapping conditions unnecessarily.

I think that's the key word. So we do have the wherewithal in this State to respond to the needs of those children between birth and six years old. We want to do just that.

As I mentioned, we had hearings around the State, we tried our best to identify parents so they would have an opportunity to testify to us. It is always easy, as you well know, to find experts, legislative experts and departmental experts, but it's my consensus and that of the entire task force that the best experts are those parents who are, what I call, in the trenches, on the front lines every day and the advocates who are out there trying to provide services. We tried our best to get responses from them.

The families became the keyword of what we try to do. What can we do and what type of services need to be provided to ensure that that child comes to term, the fetus who comes to term is born, is born healthy, lives and lives without handicapping conditions. It became obvious to us we needed to provide services that offer the support of that integral family unit, keeping that family together, that natural family, by providing services to them.

We also recognized very quickly that obviously the risked infants are cumulative and need to be dealt with with the continuance of services and not in the patchwork pattern as they had been dealt with in the past.

We know that the children are very, very important. We keep going back to that, keeping our focus on the needs to provide a quality life for the children in this State. In the State of Florida, more children grow up in poverty than a great number of other States.

In 1979, 20.4 percent of Florida's children under age four and 62.5 percent of children under two in female-headed households were living below poverty and these numbers are increasing every day.

In Gadsden County, Franklin County, and Jefferson County that number is over 40 percent of the children between the ages of zero to four. In this area of Hillsborough and Pinellas County, 9.3 percent of the individuals are living below the federal poverty level compared to 17 percent of young children.

For these families, primary health care is often difficult to get because Medicaid in Florida serves only 34 percent of the children living below poverty level.

Most children are born to young families, many have no medical insurance. Again, Senator, this is testimony that you have solicited and heard in Washington. There are some services like Medicaid that will provide medical services to children, but the new phenomenon that we have are parents, both the head of household, male and female both employed, but their employers do not provide the health policy that will provide the dollars to ensure health care to these children. So it's really a medical need type of situation, because the impact, financial impact, on the parents are so great that they just cannot afford to provide the medical care and don't have the health insurance because of rising premium costs in the State of Florida.

I mentioned that more children are born to young families. And one incident I want to report to you that I was recently in Palm Beach County, in a particular hospital, they said 75 percent of the women who came in with no prenatal care before they went into labor, both she and her husband were both employed but had no insurance to get them there, so that is a very critical point.

In Florida, every five hours an infant dies before its first birth, and as I was reviewing these comments this morning at breakfast I was thinking before we recess today we will lose another child in this State that has not yet attained the age of one. Every 42 minutes, a low birth weight baby is born. That is startling because it reminds me that before the testimony that I give and in answers to some questions and before we recess today, if you look at that 42 minutes, that means that's how many low birth weight babies are born as we sit here this morning trying to effect new policies.

While reduction in Florida's infant mortality rate has been dramatic, low birth weight has remained at around 7.5 percent for the last five years. We've actually had an increase in the number of sick babies and the severity of their condition in our neonatal units. This is due to Florida's growth, advances in the technologies which allow us to keep very sick children alive who heretofor would not have survived. And obviously you are familiar with the neonatal intensive care units. And also there is a new phenomenon, that is, the babies who are born to drug-addicted mothers. I talked to Dr. Bryant of Broward General, he said on some given days as many as 50 percent of the babies he delivers at the neonatal intensive care unit, their mothers were doing crack cocaine in the latter part of their preganancy, which obviously is a very traumatic experience for the child. We have that phenomenon, that of AIDS, unfortunately some mothers knowingly getting pregnant, knowing they have AIDS and knowing that that child when it's born has a finite period of life to enjoy.

That's a new phenomenon that we have to contend with in this State as we look at the issue of infant mortality.

This year we've collected county data on preschoolers and found that 75,000 children age zero to five in our State were involved and indicated reports of child abuse.

This represents a staggering 8.4 percent of all the children between zero and five in Florida are subject to some type of child abuse.

Many young children become handicapped due to abuse and many handicapped and at risk children are abused. In fact, the numbers are much higher, a child born to a teenage parent is four times more likely to be abused and a handicapped child born to a teenager is much more likely to be abused, so that is a very critical issue.

More than 50 percent of our high risk infants and young children do not get routine checkups and immunization. That's very, very critical and we are trying to expand both EPSDT program perhaps and make sure there is money in the budget for haemophilus-influenza vaccine.

In 1983 to 1985 ten cases of pertussis were found in children five to nine years old, and 246 cases were found in children zero to four.

Everty thirty-five minutes in Florida a baby is born to a child. That's a phrase that we coined because there is no other way to put it when you look at it.

In 1985 there were 632 babies born to girls under the age of 15. And after we recesed the legislative session last June, in the month of June two 10-year-old girls gave birth in Dade County. That is becoming a very, very critical problem because we all recognize the at-risk factors of those babies who are born essentially to children.

Now, those absolute numbers are a little bit misleading, because if you say there is a stabilizing number of teenagers who are giving birth to babies, the other thing that you have to look at is how many abortions are being performed on girls under the age of 18, so you need to take both of those factors into consideration because it can be misleading to assume that we made progress when indeed that other factor needs to be taken into consideration.

Risks to families with young children are further stressed by shortages in appropriate services and personnel. This is a real human tragedy, because it's a preventable story.

I will tell the story to you as it was told to us by 11 statewide forums. We learned that the service system was a maze of uncoordinated often duplicative underfunded programs that made providers and parents frustrated as they attempted to get a child or pregnant woman the service support to prevent long-term damage.

Medical providers talked of the human and monetary cost in low birth weight babies born to pregnant women who cannot afford prenatal care and of the 8,000 women who walked into hospitals with absolutely no prenatal care in this State.

The obstetricians spoke of liability rates forcing them out of the business. They told us of infants and children waiting in hospitals after medical discharge and were given over the State for foster care. That is euphemistically written. Essentially, what that means is that we have children in our State hospitals who have profound and severe retardation who their parents just leave at the hospital.

Jackson Memorial in Miami literally has babies waiting in the hall with profound complications and the parents just said, "We can't take it" and walked away. Those children have been abandoned to the State to provide some kind of services to those babies.

The sad fact is that if a parent with a medically vulnerable child wants their child to get specialized health services, it might be better to give that child to the State for care than trying to deal with it themselves.

Parents and pregnant women unable to afford health care told of waiting for hours at County Health Units and CMS clinics for checkups or immunizations, or to get help because their child was sick.

The clinics and doctors told us that services to children were underfunded and the reimbursements were different from program to program creating a paperwork nightmare. The Medicaid program reimbursements to a professional for EPSDT, a preventive service, was as low as $10 reimbursement to each of the doctors. Obviously not a financial incentive to provide the service.

I will hasten to add though that in the Governor's budget he is proposing to double the EPSDT reimbursement and the Preventive Task Force has recommended that doubling of reimbursement for that health screening.

Last year this program saved $273 for each child or $23.4 million for all Medicaid children age zero to 20 who participated in the program.

Parenthetically, I will tell you a study was run in the State of Texas which reflect a seven to one cull savings if you administer the health screening early on and treat that problem then rather than waiting for it to further exacerbate itself and maybe provide services rather belatedly down the road at a great deal or more expense.

They told us of quiet desperation that occurs to a family with a medically vulnerable child, how marriages and personal lives and bankruptcy are almost inevitable when the family decides to keep the child at home.

The pregnant women and high risk handicapped children cannot wait for help. The fast-growing minds and bodies will not wait. It is essential that at the federal and State level that we approach the problems of young families at risk with comprehensive solutions.

Our research identified infants and children in our State whose risk conditions could be prevented or ameliorated: Infants born too soon or with other risk conditions; children born to children less than 18 years old; children who do not get regular checkups; at risk and handicapped children without thereapeutic or developmental intervention; and abused and neglected children.

We identified some cost effective, efficient programs that saved lives, prevented disabilities and minimized high risk conditions. For instance, quality, early, regular maternity care; programs to support teen parents to prevent teen pregnancy; health care for preschool children; education and associated services for handicapped high risk children zero to four; support services for families with high risk and disabled childen; local planning and advocacy.

Last year with the help of the Legislature, and I might say under the leadership of Jon Mills who is a prime sponsor, we passed the first Handicap Prevention Act at the State level that's ever been passed in the Nation.

The act provides the means by which agencies, the Governor and Legislature can assess the status of prevention services in our State with the intent of gradually funding these services.

We'll talk to Representative Mills about how gradual that might be later on. I'd like to think of Jon as a Daddy Warbucks.

Florida has already begun to take advantage of Public Law 99-457 which supports mandatory preschool education for handicapped three and four year-olds and provides grants to the states for high risk handicapped infants and toddlers.

We would like you to be aware of how some federal programs are affecting Florida efforts at prevention.

First, block grants for programs that prevent and minimize handicaps have not kept pace with Florida's growth or cost of living increases and we are seriously falling behind in areas such as WIC, the food and nutrition program for pregnant women and young children, and Title V which supports our Maternal and Child Health prenatal programs for the medically at risk children.

Secondly, as Congress reviews the issue of catastrophic funding for the elderly, please do not forget the special and important catastrophic health care needs of families whose children are born with serious medical problems.

Thirdly, a home and a family is an absolute need for young infants, especially those who are medically vulnerable. If home medical care was the first priority in utilization of Medicaid funds for young children, fewer children will not be left in hospitals.

Fourthly, we all need to work on interagency coordination and case management. That is something that I am planning to have a better opportunity to do this year in the Medicaid legislation and preschool education legislation which is available.

Next, the manpower shortage issue is very important to us, because in the State of Florida only six percent of obstetricians and pediatricians participate in Medicaid. In 23 countries in the State we don't have a Medicaid-participating obstetrician, in 19 counties we don't have an obstetrician nor do we have a nurse midwife, and 22 counties are without a pediatrician in the State. So the National Health Services Corps program is critical to us, because two hundred physicians in this State are placed in our rural medically underserved area. And the national administration has proposed to phase out that program and by 1990 we will have zero placements in the State. You need to go back and look, if only six percent of the obstetricians are participating in the Medicaid program, and that's only three hundred plus, if we lose two hundred some from the National Health Services Corps, then these counties will be further back and the children will be further denied the services.

In closing, I will say that Florida and the Nation's young children deserve a chance, as you well know, for a healthy and productive life. These little ones have been in the waiting list and the cost of waiting for them has become too high.

Unfortunately, for many children that has become very finite: 12,342 low birth weight births in Florida in 1985; over 15,000 children born to children under the age of 18; 70,000 children who do not get health checkups; 75,000 preschoolers who were abused; 10,000 handicapped children who need special education; over 20,000 on the waiting list for subsidized daycare so their parents can attend work and/or finish some type of training; children born to addicted and sick parents and families with medically vulnerable infants.

In closing, Senator, and on behalf of these parents and these children and the children and parents that are here, we would like to again thank you for being here and we know as usual you will take this testimony to heart and to action. Thank you.

Senator CHILES. Thank you very much. Dick, that was an excellent and very comprehensive statement and I appreciate your taking time to be here and talk about this problem.

I'm impressed by the work of the Prevention Task Force and your role as the chairperson. I realize that the task force is a relatively new effort beginning in 1985, but it already seems to be working to meet its charge of preventing and minimizing handicaps for young children by focusing on the maternity care in the first 60 months of life. I congratulate you on that and I hope your valuable work and its impact will continue to grow.

What is your opinion as to why we're not beginning to experience some decrease in the number of low birth weight babies in the State of Florida given some of these steps that you're already telling me that Florida has taken? Are the statistics just sort of running behind?

Mr. BATCHELOR. I think there are several factors. One factor is obviously the growth, even though we've had stabilizing percentage rates on the infant mortality, growth is one of the factors, because we still have twenty-four percent more children who are born with handicapping conditions, so as the growth continues the rate stabilizes but the number of children affected are increasing.

Second, I think the medical technology, prior to our comprehensive neonatal intensive care unit which we started funding in 1975 in the legislature, frankly, 50 percent of those children who now survive would ordinarily have died at birth or before birth.

Senator CHILES. Right.

Mr. BATCHELOR. 50 percent of those children ordinarily who would have survived would have been profoundly and severely retarded. Great care, particularly institutional care, to the tax payers. So the third factor is, frankly, we are not just providing the level of funding that is necessary to address these problems. We are big, as you well know, in prevention, and you alluded in your opening comments, it's a matter of philosophy, we just have to try to continue to convince the full legislature and not just members of the leadership that if you put the money up front, if I might overly simplify it, if you spend $350 on the improved pregnancy outcome program and identify that mother, make sure she gets good nutritional care and good medical care, that baby will come to term and have a better chance of living without any kind of a disability. Or if you wait to spend $10,000 just for the delivery in the neonatal intensive care, it's good that we have it, so we need to fund the prevention, because if we don't to that, first of all, the cost factor is a million dollars for institutional care for the average life of a profoundly handicapped child or if it becomes an adult.

More importantly you alluded to in your comments that you can never weigh the sorrow of both the child and the parents involved in that. So those are three of the factors.

Senator CHILES. This figure that you gave of $23 per child, how do we quantitate that figure? How do you come up with that figure?

Mr. BATCHELOR. If you look at the Early Periodic Screening Diagnosis and Treatment Program, that in itself is a mouthful, I'm watching the court reporter as I say this at 78 rpm, that's the EPSDT, if you look at that program alone and we are not providing—about 50 percent of the children are not getting that health screening. If they get that health screening early on and we diagnose a medical problem right after birth, we can attend to that problem. We can delay any further exacerbating condition. As I referenced earlier, the State of Texas looked at their program and said for every dollar we spend by diagnosing that problem early and treating that problem, rather than waiting until it becomes very complicated and costly, there is seven to one cull savings. That's how we arrived at those numbers.

Senator CHILES. This is a definite number based on statistics that are taking place in Florida. We ought to be able to show anybody these numbers.

Mr. BATCHELOR. Yes, sir.

Senator CHILES. You mentioned the National Health Service Corps Program. I want to assure you, in spite of the President's budget, that Congress is not going to phase out that program. That is not going to happen.

Why, in your opinion, are pregnant women failing to get early and adequate prenatal care? Is it because care is unavailable, or is it because they don't know that it's available, or is it some combination?

Mr. BATCHELOR. Think it's a combination, Senator. First of all, as I mentioned earlier that we're in this dilemna now where Medicaid and CMS providing services to some people who qualify and meet that eligibility. Then you've got this whole new cadre of people who are both employed so they don't qualify because they are not below the poverty level, just barely above the poverty level, but cannot afford the very expensive premium for health insurance. So they don't have the reimbursements available to them.

I think we can improve that some, as I'd like to add, with the new legislation. We might be able to take some of the programs and match them and maybe go and change eligibility level to exceed the poverty line by a few percentage points to provide that.

Secondly, I think as a matter of education, it's also important to note that a lot of people, which has always frustrated me, have this opinion that only low income people have babies with handicapping conditions or only low income people don't seek prenatal care. To the contrary, if you look at the numbers, over 50 percent of the low birth weight babies are to people who are in a very substantial income group. One of the key factors is education. Getting to that person and saying this is what you have to do.

The third factor is in our county health departments, the frustration of some counties, you might say, between the hours of ten and noon or next Tuesday you can come and get in line. That's a massive frustration for someone who is also trying to work to be able to pay the cost of the delivery of that child.

So I would say that education and the cost of insurance is a deterrent to care and I would say inadequate funding at the county and health department level.

Senator **Chiles**. Has the Prevention Task Force been able to determine how many pregnant women will be eligible for prenatal care under the expanded Medicaid program.

Mr. **Batchelor**. Yes, sir, we think the expanded Medicaid program if we can get full funding which will be about $75 million to provide our state's share to match against the SOBRA, we can provide services next year to twenty thousand plus more children who heretofore have not been eligible for those services.

Senator **Chiles**. Well, I thank you again for your testimony and for the good work that you continue to do. We certainly look forward to working with you. We want you to continue to advise us as we bring the Commission into being and begin its studies and its deliberations.

Mr. **Batchelor**. Thank you very much, Senator.

Senator **Chiles**. Thank you.

For our next witnesses, we are going to have a panel and they are going to speak of some of the problems that have actually occurred. We have Marianne Towler, who is a nurse midwife and she's going to introduce Rhonda Johnson and Lizzie Weatherspoon who are mothers from Tri-County Community Medical Center. Finally, we have Kay Warner, who is also going to testify for us.

First, we'll call on Marianne. Marianne is a certified nurse midwife in the Tri-County Community Medical Center from Jefferson County, and a couple of adjacent counties.

TESTIMONY OF MARIANNE TOWLER, NURSE MIDWIFE

Ms. **Towler**. Thank you.

The Tri-County Medical Center was started in Northern Jefferson County by a group of people in the community who lived way up in the very rural area in the northern part of the county who were interested in finding things that would be helpful for their community, and particularly looking at health care for the elderly, particulary home health care for people who were very much in the rural areas and unable to get transportation in to physicians even if they can find physicians who could take care of them.

As they were getting into starting a community health center for this reason, the local nutritionist and several other people in the community, said, look, in these counties, in Jefferson County and the neighboring Madison and Taylor Counties, we have the highest rates of teenage pregnancy, some of the highest rates of neonatal mortality. In Jefferson County in 1982 it was the highest rate of neonatal mortality for black people in the country. We've got to do something about that.

They asked different people for input and they said you're crazy to start a prenatal program, it's too expensive, there are the malpractice difficulties, and we have about 250 to 300 births in each of these three countries, but they are spread out, do you have enough people to really warrant a full program?

The community board and the women's center decided that even those few were plenty to start a prenatal program and discovered that nurses existed and started the program. In October of 1984 we had our first delivery.

We do cover all of the three counties. Since we started the first year and a half, we had nurse midwives and family practice physicians. In July we got a core obstetrician, fortunately we are able to hold on to more of our high risk——

Senator CHILES. July of what year?

Ms. TOWLER. July of 1985. And we've also been able to satellite out of our clinic, thanks to the Health Department's help, into the county seats of Madison, Jefferson, and Taylor and Suwannee County.

In that time, it's been a little hard to get the statistics because in 1985 statistics just came out and at that point we've only done 123 births. We doubled that in 1986.

But we did find even in that short time and given the small numbers, that the low birth weight has dropped in Madison County and the infant mortality in half in that year.

Senator CHILES. Half?

Ms. TOWLER. Half for Madison County, right.

A couple of problems, we still have the problem of distance. There are county hospitals in two of the counties that we have. Fortunately, the counties that are mid point geographically have been supportive and very helpful in our program in allowing patients to come into the hospital to make financial arrangements with them. However, we've been unable to make a relationship with any of the other county hospitals so that some people still have to drive up to 50 miles in order to come in for their deliveries.

We still have some financial problems. We've been working intensively with the State program as well as Medicaid but after the RPO program dropped the hospitalization, a lot of people have difficulty raising the money necessary to get in the hospital even with the help of the medically needy program.

Our hospital is very small, 42 beds, you blink and you don't know it's there, but it's been trying to upgrade the OB services nonetheless.

But rural hospitals are having trouble just staying afloat financially and they are taking the risk of letting indigent people come in, and letting people make financial arrangements has been pretty risky for that one hospital.

The malpractice rates have gone up. That has affected us a lot. There were in the three counties three people who were doing—three doctors who were doing deliveries when they came in. Albeit a small number, all three of them have gone out of the delivery business during that time because of the malpractice problems.

And it's been an interesting change in attitude. The prenatal care was not very available to people for a long period of time. And so you know you get used to not having something, you figure it's not that important.

But fairly rapidly people are realizing that they need to come in and as we are available they can come in to see us.

On the positive side a lot of people in these counties have gotten very excited about trying to help out with a prenatal program now that it's in existence.

In Madison County we have Project Cope which is in the high school and it's for anyone who is concerned with pregnancy who is a high school student. Of course, it's mostly to teenagers who are pregnant who are in it. Those kids come in regularly for their prenatal care, they are taking care of themselves and staying in school, where in the other two counties we have one hundred percent dropout rate in the high schools.

The other thing is that in one of the counties some people who are just interested, who worked a lot with the school children began asking them about who the fathers were and trying to gather some information to help us out and we found out that 80 percent of the fathers of the girls under 15 were 25 years old and older, and we became more and more concerned about where the source of their sexual attitudes or where the source of their pregnancies were, and worrying, as you always do, about these young women who are coming in, some of them are very confused about their own lives and own sexualities, and then going out with a baby, that we see her for the nine months and then we tend to sometimes lose track of her as she goes back into the home environment with the baby. Thank you.

Senator CHILES. Thank you very much. It really sounds like the center has had some tremendous success.

Can you give me any kind of feeling as to what you think those figures will be in 1986? You said you had the figures in 1985 and they were half in Madison County. Do you think that there will continue to be that kind of decrease for the three-county area now that you are——

Ms. TOWLER. We're hoping so. We think we are penetrating a lot more into Taylor and Jefferson County now.

Senator CHILES. Do you think you are seeing fewer low birth weight babies now than you were seeing before?

Ms. TOWLER. Yes, we're getting people earlier in for the prenatal care.

Senator CHILES. I heard you say something that I would just like to pin down. In the school in which you are counseling, you have had no teen dropouts that are pregnant in that school, as opposed to almost one hundred percent dropout in the other schools.

Ms. TOWLER. It's "not no" dropouts, but the program is keeping a large number of the young women in school throughout the pregnancy. They are encouraged to stay in school, they are encouraged with prenatal classes and that sort of thing. The program has only been going this semester. It's not even completed a semester yet but our impression is that it's going to make a big difference.

Senator CHILES. We know, generally speaking where there is a teen pregnancy, chances are that same teen is going to repeat several times if they are not counseled. Have you got any kind of a feeling where the counseling is reducing that return pregnancy or that recividism?

Ms. TOWLER. That's a very hard thing to pinpoint, a lot because frequently people will move around and you can say we've only had one person come back, but how many people have moved to another county? Again it's our subjective impression that it's making a difference but we don't have numbers.

Senator **Chiles**. You have with you today several of your clients. I wonder if you'd introduce them to us and we'll ask them to speak. I want to say at the outset that we want to thank you very much for being here. I know it's difficult to kind of come up here and testify. All of these people in this audience are here because they are concerned about this problem. They are not here out of curiousity, they are not here for any reason other than that they have some kind of burning concern about this and want to make it better. We know that your appearance is positive in helping us. In that regard, we thank you very much for being here.

Ms. **Towler**. We thank you for the opportunity. This is Mrs. Rhonda Johnson and her son Matt. I'll let her talk.

TESTIMONY OF RHONDA JOHNSON, MOTHER

Mrs. **Johnson**. Hi. You have to excuse me, I am getting laryngitis.

I went for my first pregnancy test when I was 16 years old. And for the pregnancy test alone they wanted $80 before I left, just for the pregnancy test.

Senator **Chiles**. They wanted how much?

Mrs. **Johnson**. $80.

Senator **Chiles**. $80 for the pregnancy test.

Mrs. **Johnson**. To a 16-year-old that's a lot of money. So after that my husband and I, we kept saying, well, I need to go to the doctor, I need to go to the doctor, but I put it off and put it off and put it off, and I got to about six and a half months far along in my pregnancy and I heard about the Tri-County Medical Center, the midwives, and the first visit that I went to them I had my financial workup, and I was so pleased because it was gonna be where I could afford it. So I thought I can go ahead and get my prenatal care. Well, the first I talked to them and everything and after—when they gave me my first examination, they couldn't find my baby's heartbeat. So it was, it was done too late. But after, they referred me to Tallahassee and they induced labor with that pregnancy so after that——

Senator **Chiles**. You lost that baby.

Mrs. **Johnson**. Yes, sir. That child was stillborn at six and a half months.

Senator **Chiles**. There was no heartbeat by the time you had your first examination, there was no heartbeat there? And that was the first time that you were actually examined medically was when you were six and a half——

Mrs. **Johnson**. First time. And so after I had that child my husband——

Senator **Chiles**. When you got your pregnancy test did anybody, did the doctor tell you how much the fee would be for delivering the baby or anything of that nature?

Mrs. **Johnson**. They gave me a sheet of paper as I walked out the door and on it says $1,500 just for the delivery not including if it was a boy, the circumcision or any of the after—any of the care of the baby after the delivery.

Senator **Chiles**. So that first visit when you were told $80 for the pregnancy test you were also told $1,500 for the delivery?

Mrs. JOHNSON. Before the seventh month or they dropped you.

Senator CHILES. Before the seventh month? You didn't have that kind of money so you couldn't go back?

Mrs. JOHNSON. You would see them for seven months, I guess, if you didn't have the $1,500, dropped you right there.

Senator CHILES. Now, Matt is it?

Mrs. JOHNSON. Yes, sir. He's three weeks old.

Senator CHILES. And you went through the community service with Matt, tell us about that.

Mrs. JOHNSON. Well, my husband and I were ready for another child, because it was like expecting a baby and not getting it. So as soon as we could, we wanted to have another one. So I already knew about the midwife, so I knew right away as soon as I got pregnant I would know where to go. So my first visit with them, I was six weeks, that was my pregnancy test with them. I was nine weeks when I had my first examination. And I had several sonograms and my other child that stillborn, it was born with a deformity, his entrails was formed on the outside of his body. So the first thing that they did was they gave me a sonogram and the first thing that he told me was the stomach was fine, everything was fine, so I thought it's going to be good this time.

So at six and a half months I started trying to go into premature labor and so I saw the doctor and I got put——

Senator CHILES. You did have premature labor at six and a half months but you knew what to do?

Mrs. JOHNSON. Yes, sir, even though I was doing everything right, going to all my visits I was having it anyway, so I saw the doctor and I got put on the medication to stop it, had to stay in bed for two months, but after that they said the longer that you—they told me the longer I could keep the baby the better off he would be, the bigger he would be.

Senator CHILES. So you did everything that they told you?

Mrs. JOHNSON. I did everything right. I wanted this baby really bad.

Senator CHILES. Were you smoking any or drinking any?

Mrs. JOHNSON. No, sir. I even craved milk.

Senator CHILES. But you had somebody tell you what to do and why you shouldn't smoke and why you shouldn't do anything else?

Mrs. JOHNSON. They were very supportive. Before I even had a financial workup done this time, I didn't have to go through another one, they had the last one. And they saw me even before I had to sign all these papers saying I will pay, I will pay, you know. And they were just—that's what they wanted to know, are you gonna pay whenever, you walk in the door. But they were real good.

He was born, I went into labor with him the 38th week, my water broke when I was 38 weeks, I didn't go into labor, and so just because they were checking me and kept an eye on me, they had a fetal monitor on me and they noticed that his heartbeat was going real rapidly so they knew he was in stress and they were going to have to do a C-section and get the baby. They did that and he was fine.

Senator CHILES. They did take him through the C-section but they were monitoring his heartbeat and knew that they needed to do that.

Mrs. JOHNSON. Yes, sir. After that, the next day he was perfect, a perfect little baby, all fingers and toes and everything. It was just wonderful. Then they realized that he had pneumonia in his lower right lung, because they thought maybe he inhaled something after the water broke. They put him in a little oxygen tank, scared me half to death. And after that they took him, they put him on IV for his antibiotics, they took him off of that and then he got yellow jaundice on top of that, they had to put him under the ultraviolet lights.

I left the hospital on Tuesday and I got to take him home on Friday. So I'm real happy that he's going to turn out real good.

Senator CHILES. Is he sleeping any?

Mrs. JOHNSON. He sleeps real good, surprisingly.

Senator CHILES. His daddy likes that, doesn't he?

Mrs. JOHNSON. Yeah.

Senator CHILES. That's great. Thank you very much.

Ms. TOWLER. This is Mrs. Lizzie Weatherspoon, who is also a patient of Tri-County for her last baby. She has had several pregnancies before that. Shalanda her daughter here is 11 as was her baby who was premature who weighed three pounds at birth. And then Sean is her last baby here asleep.

Senator CHILES. Lizzie, why don't you try to tell us what happened and what the difference is, if you can, between your first pregnancies and your last pregnancy. Give us a comparison of the difference that you noticed in your treatment.

TESTIMONY OF LIZZIE WEATHERSPOON, MOTHER

Mrs. WEATHERSPOON. At the time in my first pregnancy, I was living in Sebring, Florida, and we moved here to Madison. And I had heard about this, about welfare, so I had went there to get on welfare for my child. They want to know where the father were, I told them, and then they start letting the child get a check, OK.

Then at the time, you know, we didn't, you know, exactly have money to go to the doctor, you know, and when I did go to the doctor for my first pregnancy, you know, then I was about five or six months. Then they want the money right up front and I couldn't afford to give any money because I wasn't working and my mother wasn't working. And then we didn't know what we was gonna do.

Senator CHILES. So your husband was working and so you didn't qualify for the welfare. Yet, you didn't have the money to pay what they were asking you to pay.

Mrs. WEATHERSPOON. With my first pregnancy, I wasn't married then.

Senator CHILES. I see. And then carry me on through some of the other pregnancies then.

Mrs. WEATHERSPOON. With my second pregnancy, at the time I was married. My husband was working at Gulkist at Live Oak, Florida. Well, they just carry insurance for the ones that worked there.

Senator **Chiles**. So his insurance didn't cover you and didn't cover your pregnancy.

Mrs. **Weatherspoon**. No. And so I had heard about Medicare, so I went and tried to get Medicare and then they told me no you can't get Medicare because you're married. So we just tried to put ourselves together, we got rid of most of our stuff, what we had we had to sell it, to try to get money to make a arrangement to pay the doctor bill and the hospital bill.

So with the next pregnancy I have a little girl, she is five years old, she is cross-sighted, she's a little retarded. I'm trying to get help for her and I can't seem to get any help for her. I tried to get her on Medicare, they told me I couldn't get it because I'm married.

OK, now I'm going to tell you a little bit about Shalanda now. When I first found out that I was pregnant, I went to the doctor and in Live Oak, Florida.

Senator **Chiles**. Well, in those pregnancies were you seeing a doctor regularly? Were you having the prenatal care or you just couldn't afford to do that.

Mrs. **Weatherspoon**. Well, I just couldn't afford to pay the money, and I went and tried to get Medicare but they just wouldn't let me get it.

So I went to the doctor for Shalanda, and then when I found out that I was pregnant, things got a little bit better but not much. So at the time, I was still, I would say, about five or six months, then all of a sudden, you know, I started having, you know, pains, and then they called to my father's house, they told me that I might have to come in, the baby might have to come before time. And we went on to the Madison Hospital. Then they wanted the money right up front then too. And so what my husband did, you know, he didn't want to go to his parents to ask for money because he wanted to provide money for his own children, because his parents had taken care of him and he didn't want to do it.

So, OK, we went ahead the same day and went in and checked into the hospital. Then went on in and in the delivery room they told me not to push, and all of this, and they had ended up taking the baby and she didn't weigh but three pounds. Then I learned that she had to go to Shand's Hospital, she was really bleeding inside. And they got an ambulance to take her there. I wanted to go with her, but at the time I couldn't go because I was so sore and everything, and they had to call my husband off the job to come and go with her. And it was really hard on him, because he had to try to work and, you know, try to pay, you know, the bills, and they took her to Shand's and put her in an incubator. She was there for three to four weeks and she was real tiny.

Senator **Chiles**. Were you ever able to get to Shand's and visit the baby during the time she was there.

Mrs. **Weatherspoon**. Yes, I went one time, you know, they had told me at least, you know, my mother said that I couldn't go over the wire at that time, so I didn't know what that means. So I felt so guilty I wanted to see my child and wouldn't be able to see her. And everybody else was going and I was just crying. And I went in my room and I shut the door and I started crying and I got down on my knees and I asked the Lord, "Lord, why does this happen to me?" You know, and I never did come up with an answer. And then later on the phone rang to my cousin's house and he told me you got a phone call. Then they had told me that your baby is in critical condition, she might not make it, so, you know, I didn't really know what to do. I just don't know what else to say.

Senator CHILES. Well, we're bearing with you here now.

Ms. TOWLER. You said when you went down to pick him up you thought she was so tiny, you thought she'd almost break.

Mrs. WEATHERSPOON. They had her on a pillow you couldn't exactly hold her in your arms. She was so tiny. I just can't say any more.

Senator CHILES. But you didn't have anybody to help you or give you any advice during that time, or try to tell you whether you could go there, how you could go there, how you could get help, nobody to counsel you or give you any advice during that time?

Mrs. WEATHERSPOON. No.

Senator CHILES. All right. So how is she doing now.

Mrs. WEATHERSPOON. Well, she's doing fine.

Senator CHILES. We are glad. Now, you've had another pregnancy since that then. Tell us about that.

Mrs. WEATHERSPOON. Okay, I was about well, about five or six months, you know, when I had heard about Tri-County by my cousin Elaine Gibbons. And she had told them about my financial problems that I was having, and she told me, she said, you should go to Tri-County, there are some good people there.

When I first found out about them, I called them up and told them about it and they told me when to come in, and I was so excited that God had opened the doors for me, you know. So when I went there, I started talking to them and I told them everything, they did a financial workup—What do you call it?

Senator CHILES. Financial workup, yes.

Mrs. WEATHERSPOON. They did one of those and they said that I was qualified to come there and everything. And they seem like they cared, you know, they didn't say that you couldn't come because you don't have the funds to come, you know. Sean, he was really, you know, a healthy baby.

Senator CHILES. So, he went to full-term and he was a healthy baby. You got your checkups and you did everything that they told you to do.

Mrs. WEATHERSPOON. Right.

Senator CHILES. Do you think Tri-County works pretty good?

Mrs. WEATHERSPOON. Yes, I do, one hundred percent.

Senator CHILES. We thank you very, very much.

Our next witness is Mrs. Kay Warner. Mrs. Warner, we're delighted to have you here and ask you to give us your experience.

TESTIMONY OF KAY WARNER, MOTHER

Mrs. WARNER. I appreciate the opportunity to talk to you today, Senator.

I'm Kay Warner and the little boy who has been disrupting the meeting this morning is my son Clay.

Senator CHILES. We are delighted to hear from him too.

Mrs. WARNER. Clay will be three in June and he was born here in Hillsborough County, Tampa General Hospital. He was three months early and he weighed one pound thirteen ounces when he was born.

At that time he only had 50 percent chance of survival. And that didn't even go into percentages on what type of problems he might have.

We were extremely lucky, although he was early and was on a respirator for several weeks and went through the normal course of a baby that small, he came through it fairly well.

The only problem that he has right now is that he is blind. As a result of his prematurity, he has what is called areolate, which is the deterioration of the retinas in the eye.

Senator CHILES. That's because of all the oxygen to keep him alive.

Mrs. WARNER. Yes. He needed oxygen to live but as a result his vision-suffered. He gets along very well now. And he's what we consider to be, I guess, an NICU success story. I think he's also a success story because unlike many of the children he didn't fall through quite so many cracks.

He did get the earlier prevention services he needed early on and that has really helped in his development.

Like I say, he was born in Hillsborough County. We lived here for the first nine months of his life. We had, from the time he was two months old a social worker through the neonatal follow-up clinic who worked with us on a weekly basis, worked with the baby on a weekly basis and comes to the house and made suggestions and offered services in evaluating his progress.

Senator CHILES. Was that helpful to you, Kay.

Mrs. WARNER. Yes, sir, extremely.

We had a lot of questions, concerns, anybody that knows me knows I'm a very vocal person and I seek out any information that I can find.

And to have this resource counselor who could be there was tremendous, because she could answer our questions. If she didn't know the answer, she could refer us to somebody who can find the service that he needed.

We were fortunate to have this but only because Clay was lucky and born at a certain time when USF had just gotten a grant to offer these services to a select number of babies for one year. As far as I know they don't have the program anymore.

We were also fortunate in Hillsborough County at that time they had vision teachers through the Hillsborough County Schools that came to your house, again, on a weekly basis and gave vision instructions to my son from the time he was about four months old until we moved.

We also were fortunate to find—myself and another mother and a couple of mothers that are here today started the parents support group for parents of premature babies or parents who had babies in the NICU unit and by being able to get together and talk to each other and talked to other parents, we became our own little referral network, our own system where if I had a problem and didn't know what kind of service to get or where to look for information for, say, respite care for my child or where the vision teachers were or if he had to get his hearing tested, a lot of the information we got from other parents.

When he was nine months old my husband was transferred to Orange County. And again because we're very interested in what services are available, I made telephone calls to find out what was available for my son in Orange County.

The system setup is a little different there. Like I said, they didn't have the grant to have the weekly case worker so we lost that. I was told at the time that they did not have the vision teacher for the zero to three-year-old in Orange County. So we lost the vision teacher.

The only program for the babies at that time was called Sights through the community college. They have a center, they mainly work with the adult vision impaired. But they started a program where they were working with babies also. We would take him to the center about twice a month and they would work with him for about a half a hour, 45 minutes, depending on his attention span on vision skills.

When we were in Hillsborough County his physical thereapy was also through the school system. It wasn't so in Orange County. We were fortunate in that we could afford—we had private insurance and we had to pay for private physical therapy, so we were able to get it but it was not available to us like in Hillsborough County.

Since he wasn't getting all the services that he was getting in Hillsborough County we realized the need for him to be in some type of early intervention program, so we started looking around trying to find some kind of preschool or someone to work with him, help him, teach him the things that we could not teach him.

That was very difficult to find. Eventually, we found there were two good sources in Orange County. There is a program in UCP, there is a program in Easter Seals, both deal with the developmentally delayed children and all different types of handicaps.

My husband and I decided that the program at Easter Seals was the one for us. We felt that they can work with him the best. But getting him into that program was not just saying, well, we think he needs to be here and you can help us. We ran into red tape through HRS. Although this was almost like a year after we had moved before we started researching Easter Seals. We discovered that his file from HRS had never been transferred, although I had called several times and said we're moving, transfer whatever you have to do, and we never heard from them and they never transferred it. It was lost for a while and everything like that. And Kathy Mayers from Easter Seals she knows, I drove her crazy calling her on the phone, I cried in her office, threw tantrums and everything I had to do and she was very helpful in finally getting that mess resolved. He was approved and we got him enrolled in Easter Seals.

And then also this time my husband gets a call about eight o'clock at night and the woman says, I'm the vision teacher through Orange County, I'm going to be working with your son. And we said, well, we were told there was no program in Orange County such as this. She says, oh, no we have a program, you know, you fell through the crack. So we said, okay, so you know they finally did start working with him on a weekly basis. His vision teacher goes to Easter Seals every week and works with him and is able to show his teachers at Easter Seals things to do with him also. But that's very fortunate that he's finally doing that.

He finally, several months ago—we're fortunate he now has the mobility instructor who works with him twice a week, teaching him skills on how to get around. It's very important for children that small to learn that type of thing. Normally they don't because the instructor doesn't start working with the children until three years old. We are very fortunate with Clay because the mobility instructor just happen to have an opening her her schedule and his vision teacher convinced her that Clay would be a good person for her to work with so she agreed to start working with him.

So just because we had a series of lucky breaks and we fought and it didn't let us stop us, we were told one thing we kept fighting until we got what we wanted. You have to excuse me I am very nervous.

Senator CHILES. You are doing great. You don't have to be nervous. If you have to you can take a minute if you want to. We're in no hurry.

Mrs. WARNER. Thank you. Like I say, he's doing very well because of the early intervention services. My concern and my husband's concern is it's not perfect, that the program he has in Easter Seals is great but there is still—it could be better. We would prefer, if we had the ideal situation, he would be in a program that was specifically for visually impaired children. He will be when he turns three but you know that's the first three years of his life, if he could have the continuous service the entire time, think how much better he would be, because that's something that he's not going to be able to make up. Once it's lost, it's lost.

There were several services that we needed at certain points in this development that we don't have. When he was small, when he first came home from the hospital, he came home with a monitor and had oxygen and at the time although I undedrstand now there is respite care available in Hillsborough County, at the time there was not when he was born. So my husband and I did not go out. We couldn't leave the child because we couldn't find anyone willing to take care of him or that we were comfortable leaving him with.

Senator CHILES. How long a period of time was it?

Mrs. WARNER. He was on a monitor for about three months, and then after he came off the monitor, to find somebody who just want to babysit a blind child is real hard.

I would say for about the first nine months of his life we really didn't go out. And we moved to Orlando and my inlaws moved to Orlando, so we had grandma to babysit which is great. But even now we can't or we don't just go off, you know, spur of the moment, go out to dinner or whatever, unless grandma can babysit, and it's only been, I would say, the last six months that I have been comfortable leaving him with an average babysitter who is willing to take care of him.

There is no respite care in Orange County. We face the problem of babies who are having babies who are facing that problem that we had three years ago here in Hillsborough County. I think maybe the most important thing that is needed in our case would have been very helpful if there would have been some type of countywide or statewide referral system where I can call and say I'm moving to Orange County and I have a visually impaired child, what services are available for my son? Or if you are moving from, you know, into the State and you don't know what is available and to be able to be told these are the services available in your area, to have those services available so they are consistent, I think, that would be very important.

And also I think it would cut down on duplicity of services. There are some things that the program Sight does in the community college that has vision teachers also does. It will be better if another child could get the service, if they can do something else instead of having the duplicity of services.

Senator **Chiles**. Right.

Mrs. **Warner**. That's really all I have to say. I appreciate, like I said, this opportunity.

Senator **Chiles**. Thank you very much for coming. Your testimony is very helpful to us to give us an idea of this maze that is out there as you go from one area of the state to another.

Can you give me any idea of what the expenses are? You all were covered by insurance?

Mrs. **Warner**. Yes, sir.

Senator **Chiles**. So, you did have the insurance? Can you give me some idea what the expenses were in the prenatal care, I mean, when you went into the hospital?

Mrs. **Warner**. I had a high risk obstetrician because I have a history of cancer. So as soon as I was pregnant—I did have prenatal care. As far as the expenses, we were covered by two insurance companies so that helps. Probably out-of-pocket expenses were not very much as far as my prenatal care, probably about two hundred dollars. I was fortunate. Again, he's covered. I was working at the time and my husband works, and he was covered by again two insurance companies. But one thing that we forget is it covers the medical expense which probably for Clay has run about $200,000.

Senator **Chiles**. That's what I wanted, some idea, because he was in there around——

Mrs. **Warner**. His first bill in NICU was $140,000. Since then he also had been—we were in the hospital on three different occasions for eye surgeries and so then his treatments, the follow-up to the doctor and everything, probably total pretty close to $200,000. But anything else to added that, the cost of the actual medical treatment, the eye surgeries that we had done were done at Duke Medical Center in North Carolina, we had the cost of traveling back and forth and the lodging and everything that goes along with that. That's not covered by insurance. So that you know is another ballgame.

Senator **Chiles**. I know it is. Right now do you think there is a good network of services that you are getting for him now? You are in Hillsborough County?

Mrs. **Warner**. Now, yes, sir. I think we've looked into the services that he needs right now, because he's almost to the magic number age three. He will be going into a vision program through the school system and I think he is getting the services that he needs.

Senator CHILES. But some of the service that he's getting here would not be available to him in Orange County?

Mrs. WARNER. No, it's reversed, we moved from here to Orange County.

Senator CHILES. Do you think the services would be available now?

Mrs. WARNER. Some of them would be and some of them would not.

Senator CHILES. Even if you were in an urbanized county.

Mrs. WARNER. Yes. And like where we are right now in Orange County, Seminole County does not have nearly the services that we have. And there is a child at Easter Seals who is from Seminole County who has basically the same problems that Clay does as far as vision and she doesn't have the services because she's in Seminole County and she's coming to school in Orange County. She doesn't get any of the extra stuff that Clay gets and she's not nearly as advanced as Clay is, and they go to the same school, because she's not getting the support system.

Senator CHILES. That's very clear. You can see that she's got the same handicap but she is nowhere near as advanced. That would be true if she didn't get the services. If she didn't get the, services that just follows.

Thank you very, very much for your testimony. And the entire panel, we thank you very, very much.

Our next panel is Dr. Stephen Pearson and Dr. Linda Stone of the Developmental Disabilities, and Dr. Steven Scott with Sun Life OB/GYN Services.

I'd like to tell each of you that I have read your statements in full. If you can give us some kind of a digest, we would appreciate that and would help give us a little bit more time with questions.

We'll start with Dr. Pearson.

TESTIMONY OF STEPHEN PEARSON, M.D., STAFF PEDIATRICIAN, FLORIDA RURAL HEALTH SERVICES

Dr. PEARSON. Thank you, Senator. My name is Stephen Pearson. My medical degree is from Yale University and I did my pediatric residency at Children's Hospital in Washington, D.C. I'm currently a salaried National Health Service Corps pediatrician working in a community health clinic in central Florida.

I admit patients locally to a private, nonprofit hospital. The majority of the patients I see are from Highlands and Hardee Counties and the southern part of Polk County. This rural area of our state has been designated a medically underserved area by the federal government.

The babies and children I see are predominantly from low income families. Many of them are migrant farm workers. While some of them are on Medicaid, most of them have no third-party medical coverage. I would like to briefly discuss the reality of prenatal, neonatal and infant care for my patients.

In 1983, Highlands and Hardee Counties exceeded the State of Florida's rates for infant mortality, neonatal deaths and percentage of births with low birth weights. As a pediatrician in these counties, I'm faced with a large number of very sick or potentially very sick tiny babies.

Until a National Health Service Corps obstetrician and I began working in central Florida about eight months ago, one health department had no access to physicians with hospital privileges. Mothers from the prenatal program had to wait until just before the baby was born to go to the hospital emergency room so they will not be refused admission for the delivery. Although the local health departments and my community health clinic now have prenatal programs, the majority of the mothers in those programs do not receive early prenatal care. As best I can estimate, about 20 percent enter the programs in their first trimester.

Approximately 20 percent of my patients are born with or develop problems within the first three days of life. The most common problems I see of a serious nature are prematurity, low birth weight, infections, and birth defects. If a new born baby is critically ill, I can transport him or her to a tertiary care hospital by helicopter, airplane, or ambulance. I locate a hospital willing to keep this critically ill baby by calling a regionalized referral service, the "Care Line" at the University of South Florida. The cost of the care can be covered by Children's Medical Services or CMS but only if the baby requires a neonatal intensive care unit. The "Care Line" and CMS perhaps are a real blessing to me and others in the rural area; however, low birth weight newborns without immediate life-threatening conditions or infectious babies who may require long hospitalization may not warrant transport out to a larger hospital and thus are under my care at the local hospital.

If I can treat them at the local hospital the question has been thrown at me is, "Who will pay the bills?" The hospital administrators are justifiably worried about their financial crisis, which I think this is due in part to the large number of patients they are treating who cannot pay their bills.

I also have had babies needing urgent diagnostic care that I can not provide in the local hospital.

Let me tell you about a baby named Judith who was born to a migrant farm worker family last December with a form of spina bifida. Although she was not critically ill, Judith urgently needed subspecialty evaluation because I could not fully assess the extent of her problem at the local hospital.

At eight hours of life she was transported through a "Care Line" call to a hospital about an hour and a half away where, in my opinion, an inadequate evaluation was done, apparently because the family had no means to pay.

This hospital then insisted upon discharging Judith back to my care within twenty-four hours of life.

While her mother was recovering from C-section surgery, her father left the fields, traveled two hours in a borrowed car to bring the baby back to me. This is a one day old baby.

When I realized that some essential test had not been done, I worried about the emergency I would have in my hands if it turned out that Judith had malformed kidneys or developed acute hydrocephalus, for example. About a week later——

Senator CHILES. Those are things that could commonly occur from spina bifida?

Dr. **Pearson**. Absolutely. About a week later we were able to arrange for a care unit referral and acceptance on the basis that spina bifida is a chronic problem. However, all of the costs of the initial transport and the inadequate evaluation that was done fall to Judith's parents who are desperately poor migrant farm workers, and the reason for that is that the hospital did not place her in intensive care so she was not eligible for CMS.

Senator **Chiles**. They've got the level where they'll pick up the costs had they put her in the intensive care nursery, then the CMS would have picked up the cost. Because they had not, they sent her back home and the parents had to pick up the costs, yet in your opinion they should have placed her in the emergency——

Dr. **Pearson**. She was not in immediate life threatening condition, but she needed extensive evaluation.

Senator **Chiles**. What you are saying and as you are showing us——

Dr. **Pearson**. These level of care and——

Senator **Chiles**. Is where the cracks are?

Dr. **Pearson**. Correct. Once low income babies are discharged from the hospital, they often do not have easy access to medical care. The private pediatrician, of which there are few, and subspecialists do not accept Medicaid because the reimbursement often does not cover the costs of the paperwork involved.

Many of the immediate case——

Senator **Chiles**. So the other pediatricians in your area, they don't accept Medicaid.

Dr. **Pearson**. Not in their offices. Many of the Medicaid-eligible do not apply for coverage because of the language barrier or the paperwork involved. The medication application seems to be as difficult as some of our recent tax forms.

Senator **Chiles**. That is very difficult.

Dr. **Pearson**. The working poor also do not qualify for Medicaid and they rarely have adequate medical insurance. Fortunately, for the chronically ill child we have the CMS program, that is a blessing, but it does not solve the problem for chronically ill children in rural areas and it does not cover actuely ill children. I think this is a major, major problem in my area.

Another example of falling through the cracks in the system, as you say, is Nora who was born last December to a young, single migrant mother. Nora was about four and a half pounds at birth and was about five weeks premature. She did not, however, develop major problems because of prematurity and did reasonably well but required about two weeks of hospitalization for growth feedings, et cetera, and she was discharged and I saw her once a week in the clinic for the next couple of months.

Then she developed severe pneumonia and dehydration. I readmitted her to the hospital in which I met patients. She almost died but came through it. She's a strong little baby but required another two weeks of hospitalization. At this point she is doing well but at this point I'm not sure who will pay the hospital bills.

Practicing pediatrics in the rural area, I'm sure, will always involve problems of distances and subspecialists emergency transports to larger facilities. However, the initial question when faced with a sick baby should never be, in my opinion, "Can the parents pay?"

I think short of a national health insurance program, several things can be done to improve the situation in the more immediate sense, and, in fact, I am encouraged that some of these things have already been discussed here today:

Increased Medicaid reimbursement rates to physicians and hospital such as it is not a money-losing proposition and people will be glad to see sick children; a change in Medicaid eligibility to include the working poor; simplification of Medicaid application process; expansion of the CMS program which is truly critical, I think; and adequate assistance to hospitals now providing care to the indigent; and adequately staffed, funded and managed prenatal care.

I have several major fears, and again I feel good about being here because I feel that we're not, in fact, alone out there, but two major fears I have are, one, that I am caring for a baby that will suffer severe consequences or perhaps die because I could not attain sufficient medical treatment or diagnostic care due to an inability to pay; and, two, I think I face the prospect of losing my hospital privileges, perhaps, because I admit so many babies and children who can't pay the bills. The hospital administrators have told me on several occasions "You've got a lot of those self-pay patient," which we interpret as no pay.

I feel it is encumbent upon us as a society to find ways to assure that health care is accessible to all children.

I thank you for your concern and effort, Senator. If I can be of assistance in the future, please ask me.

Senator CHILES. Thank you, sir. I want to ask you some questions.

Dr. Stone, I want to call on you next, if you'll give your testimony, and then I'll ask you some questions.

TESTIMONY OF LINDA STONE, PH.D., COORDINATOR FOR NEONATAL FOLLOWUP PROGRAMS, ORLANDO REGIONAL MEDICAL CENTER [1]

Dr. STONE. Good morning, Senator Chiles. My name is Linda Stone. I wear a couple of hats. I coordinate psychological services for the Neonatal Followup Program at Orlando Regional Medical Center and I also chair the Florida Consortium for Newborn Intervention Programs.

I am trying to represent today the departmental intervention program and the continuity of services that Mr. Batchelor talked about this morning.

I'm very grateful for the opportunity to present our thoughts collectively on what we need to do when a high risk infant is born, and I think much more eloquently than I could do, we had a number of parents yesterday during the testimony and certainly a number of parents today who could speak to the need for immediate family support.

The other piece that I want to talk about is the developmental monitoring and intervention for the baby. We note that these services should begin when a diagnosis is made. And with the advent of amniocentesis and ultrasound we can make a diagnosis in utero and we can begin to provide those services before the baby is born and prepare the baby for the high risk birth.

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[1] See p. 54 for Dr. Stone's prepared statement.

In any case, we are advocating intervention services again when a high risk is identified, and during those first three to four years of life we know that a child attains more development during the first four years than any other time in his life.

We also know that the birth of a high risk infant, as you heard today, precipitates a crisis for the family, precipitates a situational crisis which is backed upon other type of crisis that these families are beginning to experience or are experiencing not the least is, How am I going to pay for those services? How am I going to take care of my other children so I can parent effectively the child that is in the hospital?

The psychological process of pregnancy interrupted the parents are in no way prepared to deal with this high risk birth. They have to straddle the line between deciding whether or not to bond with this infant or to prepare for this infant's death. And, therefore, almost every parent that we see need some kind of immediate short-term intervention. We know it's a crisis for the infant because we have an immature baby having to deal with an environment which is ill-prepared. We know that these babies experience high light levels, high noise levels, all kinds of things that are reversive to them even though we are attempting to provide the best possible medical care that money can buy.

Florida has become a model for the delivery of medical care for infants. We can be very proud of the fact that we have reduced handicaps in larger infants, and we have saved large numbers of low birth weights and other medically vulnerable children.

Saving these lives is only one piece in the prevention continuum. We have saved baby who cannot survive without the nurturing of his family.

Dr. Steve Freedman in a presentation to our 99–457 Council for Infants & Toddlers Interagency presented a diagram to us that said: "Development really equal medical care plus education." Those of us in intervention want to really expand his wonderful definite figures to say that "Development really equals medical care plus family support plus early intervention."

And an infant's physical intellectual and emotional needs cannot be separated and they cannot be isolated from the family.

Development is a whole concept and facilitating must be done in an interdisciplinary way with all of us working together.

I specifically have an interest in NICU intervention program because that's what I've been working on for the last eight years. I know I really do not want to limit my comments to just NICU intervention programs. There is a paucity of all kinds of early intervention program in this state for children zero to three, and we really have to pay attention to that.

We know, however, from our particular statistics that we are keeping, that six thousand infants are admitted to our NICUs. Last year in Florida, we have follow-up data to suggest that all of these infants were at risk in one way or another. We know these families are in crisis, and there are many, many immediate in-hospital support to enable them to begin to parent their infant.

Many of these families also need support after the infants go home. The infants need intervention in-hospital and they need intervention post-discharge, transitional services are necessary. We need to begin to filter them into the existing community services and we need to beef up those existing community services.

The State of Florida over the last eight years has developed model NICU intervention programs to provide these services with a goal of integrating infants into a family unit and to maximize and develop the potential of the family and the infant.

These programs have clearly demonstrated the efficacy of these types of programs, of this type of a multidisciplinary approach. They work and yet most of them, if not all of them, in terms of the NICU programs will disappear in June of this year for lack of commitment of state funds.

We have federal initiatives under 99-456, we have the statewide initiative, the Handicap Prevention Act of 1986, and these initiatives tell us that we are not wrong, that, in fact, we are pushing for the immediate family support and very early intervention. That is being recognized by longitudinal studies conducted around the country.

Prevention of handicaps in young children means we must provide medical care coupled with family support and early intervention to maximize the children that we save and to make them productive in our communities. Some programs are losing funds, others have long waiting lists and children are losing valuable time.

I want to urge you to not have a step backward in what we are planning in this State and in the country to move forward. We must recognize and fund NICU and other early intervention programs that we know work. Thank you.

Senator CHILES. Dr. Scott.

TESTIMONY OF STEVEN SCOTT, M.D., PRESIDENT, COASTAL GROUP, INC.,[1] ACCOMPANIED BY HARVEY GARDY, M.D.

Dr. SCOTT. Thank you, Senator. I am Steven Scott, President of Coastal Group, Inc., a physician contract group based in Durham, North Carolina, and Fort Lauderdale, Florida. We provide emergency physicians and obstetricians under contract to hospitals.

I think, in effect, we represent the private practicing physician in an effort to deal with the problems we are discussing today.

With me today on my right is Dr. Harvey Gardy. Dr. Gardy is from Hollywood, Florida. He attended Tulane Medical School, did his residency in the University of Miami, and like myself is Board-certified in obstetrics and gynecology.

I trained in Indiana University Medical Center, then to Duke University Medical Center and for residency in OB/GYN and I remain in their clinical faculty of the Department of OB/GYN.

We are certainly pleased to have the attention of this hearing today to discuss this most important problem.

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[1] See p. 61 for Dr. Scott's prepared statement.

What I'd like to do, Senator, is tell you a little bit about what we do. We are of a different slant and I hope we can at least take some part of this problem and address it.

Our company started several years ago with the need to provide emergency physicians and competent emergency physicians on a full-time basis to hospitals throughout the country.

We now see approximately two million visits per year primarily in the southeast. Our biggest client being the Broward Medical Center.

Back in 1983, Broward General Hospital realized they had a serious problem in trying to coerce the private obstetrician to try to take care of the patients who had no ability to pay.

At that time, we went in providing ten obstetricians to deliver what we thought was 2,700 babies per year in that particular institution.

Since that time, the completion of 1986, we delivered 4,200 babies, indigent babies, just at Broward Medical Center.

In 1986, fortunately some other hospitals throughout your State realized again that the private obstetrician was not able or willing to always provide the care for these indigent patients, and through their operating budgets found a way through the wisdom of their board and the County Commissioners appropriated to allow us to come in and bring full-time, Board-certified, well-trained OB/GYNs to look at these patients.

The hospitals are the South Broward or the Hollywood Memorial where we delivered 1,500 a year; Indian River Hospital in Vero Beach, 600 babies; Bethesda Hospital in Boynton Beach where they delivered 600 babies a year; and Halifax Hospital in Daytona Beach with 1,200.

We are at the point where we deliver ten thousand babies in the State of Florida. The cost factor is certainly great. To give you some example, our average obstetrician will make between $100,000 to $120,000 a year. That would include benefits. We then must turn around and pay, at least in Broward County, $100,000 to $124,000 a year towards malpractice.

If you took all the monies we will receive, our cost for delivery——

Senator **Chiles**. Per doctor?

Dr. **Scott**. Per doctor.

Senator **Chiles**. He's making $110,000 and you are paying an additional——

Dr. **Scott**. $124,000 for his malpractice. We are only able, because of the limitations of the funding, to have our obstetrician in the hospital; that is, when the patient arrives we are there. The patient normally will have been, hopefully, will have been seen in the prenatal public health service. We do see about 3,500 high risk patients a year at Broward General and lesser in some of our other locations. But our average cost to Broward General Medical Center is only $460 per year for delivery of each baby, that does not include the 1,200, excuse me, the approximately 750 major and minor gynecological procedures that these patients require per year. If you were to include those, our costs for either a delivery or a gynecological procedure would be reduced to under $400 per patient for the care of these people.

We obviously have found that the quality that we can control has markedly improved. I think before it was—many times it is private medical staff, sometimes they were residents rotating through, sometimes supervised, sometimes not so well supervised.

During the last year in 1985 we made substantial improvements in the neonatal death rate. However, in the last year we have begun unfortunately to see that rise again as you probably know, with the recent increase of substance abuse. I heard Dr. Udell's name mentioned. Some of his figures have been mentioned. Approximately 20 percent of all the babies that we deliver at Broward General Medical Center that go to the neonatal intensive care unit are from mothers who are crack abusers.

Senator CHILES. 20 percent of the babies, one out of five, are in the intensive care unit?

Dr. SCOTT. The mothers are crack abusers. Those are the ones that are known.

Senator CHILES. Well, those babies are addicted when they are born, aren't they?

Dr. SCOTT. Yes, sir, they are. I need also to say the problems of smoking, alcohol, et cetera, are very substantial. Again, we are faced with only having the ability and the financial resources to provide the service in the hospital. And our program is unique in the sense that our obstetricians are in the hospital. As a matter of fact, we have a minimum of two obstetricians in the hospital, twenty-four hours a day at Broward General to take care of these patients when they come in.

Problably around 30 to 40 percent of these patients have had absolutely no prenatual care. And I know several questions have been asked today, well, why haven't these patients had prenatal care? Let me give you a very good example of a system that is supported to work but not as efficiently.

If a woman will seek the services of an obstetrician or health service provider after they missed one period, that puts her eight, nine weeks along by the time you call the health department, and because of backlog and the necessary paper log, if you are in somewhat of an emergency, they will get you an appointment within six weeks. Suddenly you move from 10 weeks to 16 weeks. If you are not an emergency then it may approach ten weeks before your appointment. At that time you could be as far as 18 to 22 weeks along in your pregnancy, which is your first trimester. We like to see the mothers as soon as they know they are pregnant and get to them.

You think that over half of our costs goes to professional liability, and that's not what I'm here to talk about, but if we did not have a great cost in that field, we would be able to double the number of obstetricians to ten at Broward General, and two at Hollywood Memorial to 28 or, excuse me, from 12 to 24.

Senator CHILES. You double them from what now?

Dr. SCOTT. If we had no cost for professional liability, we can hire twice as many obstetricians, which would then allow us to go out to the prenatal clinic. I think there are 17 prenatal clinics in Broward County and we would be able to be there with the RNs who look after these patients and try to screen them.

They have a very heavy load. They do a very excellent job, but simply, the system is overloaded. We think we do represent an alternative. This program has caught on nationally. We are getting calls from Washington, D.C. We most recently will be starting a hospital in Atlanta, Georgia.

I think the whole key is instead of taking the private practicing physician and say we want you to practice, 75 percent of your time will be dedicated to your private patients and 25 percent to your indigent or your non-pay patients, we are saying to our physicians as they come on board, your job, your life, the rest of your career is dedicated to the indigent patient, they have special needs. Some of the subspecialties in this—These patients need more education, they have more transportation problems, as we heard today, whole hosts of problems, that I think generally the private practicing physician, and I have been in private practice, doesn't usually see.

That's what we hope our group will be able to do in the future. Obviously, this is something we're most interested in. If there is anything, Senator, that we can do further, we would be more than happy to do so, but we certainly appreciate the privilege of being here today to discuss our program.

Senator CHILES. Thank you very much.

Dr. Pearson, if you'd get the mic back. I want to thank you. I understand you left a medical conference to come here today and I appreciate very much your leaving that——

Dr. PEARSON. That's correct.

Senator CHILES [continuing]. And sharing this with me.

Was there a doctor in your region before you came to the Tri-County region? I mean public health doctors, so to speak?

Dr. PEARSON. Non-pediatric. There was an internist who was present about six months before I arrived.

Senator CHILES. There was nobody in pediatrics? When will your term be up?

Dr. PEARSON. Two plus years from now.

Senator CHILES. Two plus years from now. Will there be somebody automatically to replace you when you leave?

Dr. PEARSON. Not necessarily, no.

Senator CHILES. Not necessarily. So was there a hole there before you got there? In two and a half years from now there may be another hole again?

Dr. PEARSON. There may be, yes.

Senator CHILES. And the doctors that are there, as you say, don't take assignments?

Dr. PEARSON. Well, that's not entirely correct. If a sick child comes to the emergency room the physicians rotate responsibilities for that child on a weekly basis, but they will not take Medicaid in their clinics.

Senator CHILES. Would you say there have been some pretty strong differences in the mortality rate since the time that you've been there and the other services that are being provided.

Dr. PEARSON. I don't have precise data on that, but what I'm told from the health department is that, in fact, we are seeing a lower rate, but I don't have the rates. It's too early.

Senator CHILES. How many deliveries are you responsible for covering each year.

Dr. PEARSON. When I arrived no one was really sure, because the service had not been provided before. In one county, we'll have some 400 to 450, and then our clinic as a prenatal program currently is projected to have something like 100, 200 per year, so that's 650 maybe.

Senator CHILES. Six hundred fifty. A normal practicing physician would be expected to do 200?

Dr. PEARSON. Possibly, yes.

Senator CHILES. Two hundred a year? What are your obstetricians doing?

Dr. SCOTT. Four hundred twenty.

Senator CHILES. Four hundred twenty a piece? Do you consider that to be a pretty good rate in the private sector?

Dr. SCOTT. They do—the American College of Obstetricians recommends 180 deliveries per obstetrician per year.

Senator CHILES. I see. You sound like you are a pretty busy fellow. Continue to be.

Dr. SCOTT. Pretty busy.

Senator CHILES. You said that only twenty percent of the women you see are starting or getting prenatal care in their first trimester. I think you said about 40 percent just arrive at the hospital. Are those figures correct?

Dr. PEARSON. Not exactly, I see the women when they are in the hospital, after they've given birth, sort of looking at numbers and people. It appears that about 20 percent start in the prenatal program after the first trimester, many are very late arrivals, in fact, one visit to the health department before going into labor. The 20 percent I mentioned were babies that I see in the hospital that develop significant problems.

Senator CHILES. Could you give me an estimate as to what percentage of the low weight birth baby, what percentage you think could have been prevented if the mother had received early and adequate care?

Dr. PEARSON. A percentage would be tough for me, but I think it be many, perhaps the majority. Many of the problems are preventable. Poverty is a multifaceted problem, as you know, that contributes, smoking is a preventable effect, drug abuse, alcohol, et cetera. But I think with aggressive prenatal care the majority could be probably, if not avoided, could at least be ameliorated.

Senator CHILES. The rationale of why we should get rid of the Health Corps Program is that we have enough doctors in this country today and so we don't need to encourage any more through such a system. What is your opinion of that?

Dr. PEARSON. I think that it is somewhat shortsighted and I think we have large areas of Florida that belie that approach.

I don't think there will be more pediatricians in my area in the private practice.

Senator CHILES. In effect, even if we have enough doctors we're not going to have them in the places where we need them, in the rural or impoverished area.

Dr. PEARSON. Not in the private practice at least. Not under the current reimbursement system.

Senator CHILES. I assume this helped you get your medical education, you are doing your service now as a result of doing that. Do you think that you would be an M.D. and a pediatrician today without the Corps?

Dr. **Pearson**. I think I would. I think I would. It would have been more difficult, but I think I had a philosophical commitment to this approach before starting medical school and I am very pleased to get in the system to do it.

Senator **Chiles**. Do you find other people that are like you in their philosophical approach in seeking that type of service?

Dr. **Pearson**. There are many, yes.

Senator **Chiles**. Good. I've been told that I can announce the change in the checkout time to one o'clock, so if I keep you here a little longer you don't have to get out of your room.

Dr. Stone, you had an example in your testimony. Could you briefly tell me of the child that you were talking about where these services you thought were so necessary because of the problems with that child, I think, that might be worth telling to our people here.

Dr. **Stone**. I had actually two case studies in my testimony. One highlighted the family and one highlighted the infant. Which would you prefer?

Senator **Chiles**. The first one.

Dr. **Stone**. About Neil whose family moved to Florida when his mother delivered him without a whole lot of warning in a bed in a community hospital. She was six and a half months pregnant, and they had come to——

Senator **Chiles**. Did she have any warning that he was going to have problems.

Dr. **Stone**. Yes; she actually had some indication that she was in premature labor. She had good, high-quality prenatal care, she had it in Chicago, they move to Orlando, but neither obstetricians educated her regarding the premature labor. She started cramping, she ignored the signs thinking there was noting to worry about. By the time she called, they said she was probably miscarrying, so that what happened is she got to the emergency room, the doctor walked in, her water was broken, she was left in bed to labor and this baby was precipitously delivered in her bed and she viewed him and he was born viable, he was alive, he weighed a pound and a quarter.

Senator **Chiles**. The doctor assumed that the baby was going to be stillborn or miscarried?

Dr. **Stone**. That the baby was not far enough along in gestation to be a viable infant. The baby was in the borderline area of about 24–25 weeks' gestation, and, therefore, he walked in, he was at a party, he left and he said, "You are going to deliver this baby and we'll provide you with the appropiate support." Unfortunately, the baby came more quickly than anybody thought and he also had other ideas, because he was born alive. He was left with the family because this baby was going to die. And again he decided he had a little more expectation and innerstrength and managed to survive.

And of course the whole ball began to roll. Doctors from the tertiary care came, stabilized the baby. Fortunately, this was my own unit which we provided a lot of in-staff training and they took pictures did the handholding that was necessary before the baby was moved, and as much handholding as we did, of course, the parents were still frantic.

And this was the situation of a very, very premature infant with all of the complications attendant to that, intraventricular hemorrhage and bleeding lung problem, because the lungs were immature that we had to put the baby in the respirator. While we kept the infant alive, we also scarred the lung. That is part of the ironic complications of providing this kind of care. And these people were on an emotional roller coaster, up and down, and up and down. And the first time the father came in he said, "I don't want any extraordinary measures to keep this infant alive. If he's brain damaged, we cannot handle this type of child in our family."

Somehow parents become bonded to their children whether they want to or not. So they were riding the roller coaster. Oh my God, what's going to happen if he dies? So it took intense conferences and interdisciplinary conferencing. We have a unitologist, the nursing staff, the respiratory staff, the parent counselor, anybody whose involved who is caring for this child. We hold regular family care rounds where we discuss the cases. We do that every other week. The intervening weeks we have development intervention rounds where we work with the children at high risk. We have nursery care plans to serve the immature needs of these children and to begin to integrate the familes into the care of these children. We have earlier discharge, we have smoother transitions. We are able to have alternative service delivered and reduce the number of days that the child is in the hospital, even the very, very involved children. So we know it's working, we know that we are helping parents cope. We are helping them do the job.

Senator CHILES. What you're telling me, as it was with this child, and the question was whether this child is going to live or whether this child is going to die. If the child is going to live, he is going to be terribly handicapped, or if he dies, all that you were trying to do to help them through and give them answers and to allow them to talk and get those feelings out and what kind of a situation would you say, you know, what happens without any services like that for the mother or the child?

Dr. STONE. You know, parents think they're going crazy. They think that there is something the matter with them to have these feelings. They don't know what to do with the feelings. We had someone testifying theat they kept the feelings in for a year, two years, and all of a sudden it comes in an adverse kind of way, not the least of which is making the decision: I cannot cope, I cannot take the child home, I cannot take care of this child.

We have children that die in our hospitals waiting for some kind of medical foster care because no one is there to take this child home. We have had a child—we had a child named Wayne, he was ready for discharge at about five months. His mother was not able to take him home without the appropriate support services. We attempted to get alternative delivery for him in the sense of a medical foster care home where she could come in and begin to learn the skills, and in going through the red tape of HRS, which all of us know about he died. Clearly and simply.

Senator CHILES. You think he died for just lack of——

Dr. STONE. He died of neglect, he died of the system not understanding what is necessary for these kinds of children.

Senator CHILES. Are there ever situations where you become involved with a family that's been notified—well, you gave us that one example, and you gave the kind of services you mentioned, some legislation that would provide neonatal services statewide? Is there an estimate of the amount of money this would cost to fully fund it. We were talking about this last night, to fully fund tertiary care and a center with this type of program? This would be $4 million? We are asking $2 million for this year with the hope that we would also build up the CMS developmental program, that is, the follow-up services that is discharged from the unit.

Now, would you tell Speaker Mills and myself and others as to where the cost benefit of this could be?

Dr. STONE. Well, that's interesting, because that's being studied nationally. The cost benefit are what are we doing as far as minimizing the handicaps of children with very involved handicaps, we are raising the points by ten, a gain. But I think the real gains in the kind of program that we provide is the fact that we have integrated these children into the family system and that we are allowing parents to do the job that parents should do.

Senator CHILES. It's got to have something to do with child abuse, do you have some kind of counseling and training——

Dr. STONE. We can reduce the incident of child abuse, we can begin to work on the stress of the parents.

Senator CHILES. In effect, you are saying we don't know how to quantify it but we know there are tremendous cost savings there as well as the suffering.

Dr. STONE. The cost savings is we have a child at home with the family where it should be.

Senator CHILES. Dr. Scott, what are you paying in the way of the total malpractice insurance coverage for your operation in Broward County.

Dr. SCOTT. About $124,000 per obstetrician.

Senator CHILES. What is the number?

Dr. SCOTT. Over a million dollars, about a million two.

Senator CHILES. What kind of exposure have you had since you've been there.

Dr. SCOTT. Fortunately, Senator, we have had a very excellent track record. I think there had been some unhappy events prior to our arrival, but I have long contended that obstetricians tend to make mistakes when they are not in the hospital. They get a message from the nurse and they either are not quite sure how to intrepret that nurse, should you go in, should be there with the obstetrician in the hospital? We simple go over and look at the fetal monitoring strip and make a decision. Is a C-section necessary? Or no, if the baby is okay for the moment, we can wait for 15 minutes. There are no other outside distractions interms of private practice.

We have enough in the staff if there is a high risk we can send the perinatologist or others to look in the clinic.

The highest award that has been paid today, we started in 1983, was $24,000.

Senator CHILES. Are you getting any reduction in your rate because of that?

Dr. Scott. No, sir. We have argued that but they tend to think, if you do a good job you get no credits, if you do a bad job they kind of get rid of you. I'm not sure.

Senator Chiles. Well, you know, we don't have a system in which there is no competition, so to speak. So in spite of the fact that you are having this kind of care and you are having this kind of issue, you are paying $1 million a year and their losses are virtually zilch.

Dr. Scott. That's right. We obviously compared various carriers around the State and nationally, and many carriers nationally and even within the state, would not accept our group for the reason that they felt we were dealing with all high risk patients, or a lot of high risk patients, and certainly we do. But in spite of our four years of relatively good success and being very attentive, we have not been able to get any rate reductions to date.

Senator Chiles. The county basically feels that what they are paying you for those services are justifiable. They are keeping you on. But that's a cost benefit for them as opposed to the way they were doing it in the past?

Dr. Scott. Yes, I think they have been very pleased. We have in our contracts that we will not care for any private patients unless they are unassigned and show up without a doctor. And we certainly don't want to be in any competition, if you will, with the private practicing physicians. We are there to serve the patients who cannot affort these services.

Senator Chiles. What do you do with the people with limited ability to pay or the family who has some limited ability, how is that handled?

Dr. Scott. Fortunately, in Broward County that is the most difficult group. They can't get in the medical department. The average delivery fee from a private obstetrician is somewhere between $1,800 and $2,200 in Fort Lauderdale, and they can't pay that. So they end up many times coming to the emergency room ready to deliver, in labor and never having seen a doctor.

Senator Chiles. So you deliver those but you don't pick them up earlier, the health carrier?

Dr. Scott. We can't get them into the system as it exists today.

Senator Chiles. This is making up the number—was that the one that you give me the figure of 40 percent?

Dr. Scott. Right.

Senator Chiles. That sounds terribly high in Broward County, an urbanized county out there, how in the world can it be 40 percent?

Dr. Scott. Let me ask Dr. Gardy for his comments.

Dr. Gardy. Actually, some of the hospitals that runs over 50 percent, the nurse midwives in some of the hospitals are key statistics and they label these patients walk-ins. Some of them run 50, 52 percent.

Senator Chiles. Obviously, that's the percentage where you have the highest number of the low birth weight and the problem babies because no one has seen them and they haven't had any prenatal screening and information.

Dr. Gardy. Yes, sir.

Senator Chiles. They don't know about smoking, they don't know about the other things?

Dr. GARDY. Exactly.

Senator CHILES. You don't have a high migrant worker population there, I guess you have a lot of Haitians.

Dr. GARDY. They have a large Haitian population.

Dr. SCOTT. They mentioned a patient which is underinsured. Without mentioning names, we recently signed a contract with a privately funded organization that's into social problems, and we provide the prenatal care and the delivery. The hospital provides a facility for delivery and includes pediatric care. That comes in at just about 50 percent of the going rate in that county.

Senator CHILES. Now, explain that to me again.

Dr. SCOTT. Well, essentially in South Palm Beach County we signed a contract with Planned Parenthood and we are currently about to sign one in Broward County. They take pregnant women who make between $10,000 to $25,300.

Senator CHILES. So they are looking for the gap.

Dr. SCOTT. Yes, sir. If they are in that income group, then they have to pay $1,900. They get prenatal care, delivery at Bethesda Memorial Hospital at this time, in-house obstetrical care and pediatric care and post-partum care, and I believe several well-baby visits all for that $1,900.

Senator CHILES. That's about half of the going rate of what it would be.

Dr. SCOTT. Half or less.

Senator CHILES. Half or less?

Dr. SCOTT. Yes, sir.

Senator CHILES. Is there some kind of arrangements to how they can pay that, and set it up too?

Dr. SCOTT. Actually that works between Planned Parenthood and——

Senator CHILES. Your contract is with Planned Parenthood?

Dr. SCOTT. Yes, sir.

Senator CHILES. That's something that just started. You see that as being very beneficial down there?

Dr. SCOTT. Well it's gotten a lot of wide acceptance from the patients down there. It started two weeks ago.

Senator CHILES. Well, that sounds interesting. I might have several other questions I'd like to maybe submit to you to try to get you all to submit responses.

Thank you very much for taking your time. You all went through some trouble to get here. I know you came from Durham, we thank you very much.

Now that we've had the chance to look at some of the problems, we'll bring up the man with the answers, Speaker Mills.

Yes, I do want to thank you very much for coming. I understand you do have another engagement. I want to compliment you again in not just being here but for listening. I found a long time ago when I listened that's when I learned something, and I know you found that too. You've always been a listener, you've helped chart a lot of ways in Florida and in a lot of legislation having to deal with water and crowded housing and a lot of other things that we're delighted to see your efforts now in this deal.

TESTIMONY OF REPRESENTATIVE JON MILLS, SPEAKER, FLORIDA HOUSE OF REPRESENTATIVES [1]

Speaker **Mills**. Thank you, Senator. The group that will be waiting is the FMA so I figure they can handle it.

I really do appreciate the opportunity to be here. First, I want to say that I appreciate what Dick Batchelor has been doing, what his organization has been doing to elevate the issue, to bring this issue to really a state at which this year is a tremendous opportunity.

I think because of what's happening in Florida, because I think we realize that this is Florida's chance to move forward and either we are going to do it or not, it's a good opportunity and I really thank Dick for what he's doing. I know what he's going to do. It's always a privilege to work with you, Senator, I know you mentioned earlier that there is a Lawton Chiles IV. And as you know your son and I are pretty good friends. When Lawton Chiles IV was born, they were under no extra pressure just because the child was named Lawton Chiles IV, and they responded admirably. And it's great to see you, see how he's doing.

Florida, interestingly enough, we recanted all these problems. In some area we were doing a good job in neonatal care. In other areas, Florida is truly borderline embarrassment. We have a lot of statistics.

One statistic I enjoy using, and we'll use it at lunch as well for the FMA, is we are 51st among the States and I ask, "Was there a State admitted while I wasn't watching?" And the answer is the District of Columbia is included in the statistics on public assistance and we are 51st in the public assistance, which we are with the borderline third world nation. That's Florida's fault. We are 46th in mortality and 48th in high school dropouts, and all of those really follow on from the very beginning.

One of the things I want to comment on, and I'm not going to read this testimony at all, is that direct experience, which you're providing for all of us and for yourself, is one of the best teachers about these kinds of issues.

We can read data about being 51st is fairly cold. I don't know what that means. But when you have a chance to see the mothers and the children——

Senator **Chiles**. I was thinking that and I was thinking, you know, I wish that every member of the Florida Legislature could have heard this testimony this morning. I wish every Member of the Congress, House and Senate could have heard this testimony, it would be very, very fulfilling.

Mr. **Mills**. I was thinking the same thing. I don't know if we can get the numbers, but we can expand that at one point we shared the HRS Criminal Justice Appropriation in the House. One of the things that made me most interested ultimately in child abuse and early childhood medical care was one of the obligations in that committee was a travel to our institutions and the mental health developmental disabled correction. What became very clear to me are those institutions are populated by either abused kids and kids who have birth defects.

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[1] See p. 65 for Mr. Mills' prepared statement.

Based on some of the consequences we've discussed and the direction and specific personal misery and the cost to the State and the public is a crime. And we I think now the more we can explain that, the more we are going to be able to get the resources. And the data that we have, interestingly enough, on infant mortality in Florida we rank in the same area.

I think I mentioned that before. And the question is, "What are we going to do about this?" I'll give you a summary of what we're going to try to do. And, frankly, the public policy in Florida this is just one of the areas that I think we are at a turning point. This is really Florida, this is the best of times and the worst of times. We are under enormous pressure in terms of growth. We are in enormous danger of where we can go. If Florida were a patient, the vital signs are marginal. We look good but we're not sure that we are going to be okay.

The first thing we are going to do is try to repair the public and medical assistance fund which was an attempt to implement the medically needy program and, through the raising of revenue, to pay for indigent care in hospitals.

Well, the combination of paperwork, et cetera, we were told there could be 178,000 new people eligible. And basically the program hasn't worked. We are sitting with $180 million in trust and not spent. So this year we are going to redo that and not base it on individual Medicaid but enlist a formula to direct it to the hospitals who are willing to do the care.

It should solve some of the problems, it should help some of the programs that have been mentioned here, particularly the Tampa General Hospital and Jackson Memorial will get the lion's share.

As we go down the list of hospitals who are willing to provide indigent care, we also want to emphasize early childhood care and care for pregnant women.

The SOBRA program was mentioned earlier. It will be our proposal to handle, to fund SOBRA from general revenues. The Governor's proposed funding for the public medical assistant funding, we propose to fund from the general revenue. We show a commitment. We are also funding from age birth to five rather than age two.

Senator CHILES. So you'll expand it to age five.

Mr. MILLS. Yes, to age five. And interestingly, the data on that is worth mentioning. It's probably worth mentioning if you can say to the Rhondas and Lizzies there will be 30,000 additional women available for care and 55,000 additional children under a program if he——

Senator CHILES. Is that by expanding it from two to five or——

Mr. MILLS. The entire zero to five. The second thing we'd like to do is SOBRA leaves off at age five. We are trying to do something that is directly a state program from age five to age ten with the same guidelines. The expansion of this program is to go all the way up to the Medicaid guidelines. In some cases that's going to triple the income level, that's why that many more people will be involved.

We are also interested in trying to deal with—physicians' fees were alluded to earlier, that physicians' fees in Florida, I guess, have not been changed in about 16 years. And so what we're going to propose will probably entail as much as doubling some of the fees for Medicaid-eligible and we hope—we heard the data earlier and are aware of the six percent who are willing to qualify and we are hoping that more will be willing to do that.

Basically, the issue in Florida will be funding, which is not new. One of the interesting things is everybody criticizes the federal government for having a federal debt and Florida is always very proud that we have a constitutional amendment that requires a balanced budget.

I think the evidence here is we do have a debt and that we've just failed to fund programs that should have been funded, so we balanced the budget on the backs of the people who can least afford it.

And very, very simply, Senator, we are going to make our best effort in this area. These programs are cooperative and to the extent we can educate our folks and you can educate your folks, we can do a better job and help the needs of all the parents and all the organizations. I appreciate the opportunity to be here.

Senator CHILES. Jon, I thank you for your statement, your appearance and your interest. I think you'll agree with me that basically this is a problem that is as much of a communication and understanding as anything. You and I both know that the people of this State are willing to see that no mother is turned down because of cost and no child is turned down for treatment because of inability to pay. And we as public officials have the jobs with all the other people to convince them that this is what the people are all about. We are not talking about a giveaway, we are not talking about a handout, we are talking about an essential service that any human being is entitled to.

And as I say, I know that the people will respond to that if we put it to them the right way and I know that you do too.

I think we are very fortunate to have you as our Speaker this year. I'm tremendously proud of the Flordia Legislature. I'm proud to be a preacher of that, and I say it often, because I thought when I left Florida and went to the U.S. Senate I was going from the minor leagues to the big leagues. I found that it wasn't exactly true. Florida is ahead of progress. Much of what is done in the areas that we are working on, handicapped many of the years where the federal government was, and I continue to watch with great pride what Florida is trying to get in front and part of this Legislation that we have inherited the 51st rank. I know we are ready to do something about that. I think with your leadership you are going to see that that does happen. I hope to help you in some way. We really need your advice and the advice the legislature as we go forward with the Commission. We want the Commission to come up with some sort of a national blueprint for how we mesh the federal role and the State role and the local role, and how we provide those necessary services. And we know that Uncle Sam is not going to provide all of it. We are talking about money from the State and local government as well.

As you well know, with the tremendous deficit that we have, pressure will continue and we are going to have to see that we make some funds available in this area. And we get sort of the best cooperative leverage for our money to see that we do get those county commissioners involved, to see that we do get the local services involved and get the State involved, all of us participating. I sort of scratch my head as to how we are going to do that. We need your counsel and your advice and we look forward to working with you. Thank you very, very much.

Mr. MILLS. Thank you.

Senator CHILES. Well, I want to thank the Parent-to-Parent Conference for helping facilitate our hearing and for each of you for your appearance here.

It's been a most interesting hearing for me. I know that I've learned some more, I know after listening to the statements here today, especially from our mothers and our people that are on the firing line, I am more and more determined to see that we produce a product in the Commission and that we try to come up with a game plan to put it into action. An action plan, and also to see that we try to broaden some more of those services in Medicaid having to do with intervention for children and teen pregnancies and infant mortality. All of those particular areas.

I'm confident that your work and what we're doing here is the Lord's work and I look forward to continue working with you.

Thank you very, very much.

[Whereupon, the hearing was adjourned, to reconvene at the call of the Chair.]

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

Statement by Dick Batchelor at the Congressional Hearing on Infant Mortality and Child Health

The Honorable Senator Lawton Chiles, March 21, 1987

Senator Chiles thank you for allowing me to share the findings and recommendations of the Prevention Task Force on infant mortality and child health in Florida.

The Prevention Task Force was appointed by the Secretary of HRS and funded through the Florida Developmental Disabilities Planning Council to develop an action oriented state plan to prevent developmental disabilities, to reduce infant mortality, and to minimize the effect of disabilities.

We studied state and federal research.

We studied programs that were working across the nation and in our state.

We listened to testimony by parents and service providers at eleven statewide forums attended by over 2,000 Florida citizens.

I was frankly shocked by our findings, but I was also heartened by the fact that Florida has the technology and the dedicated professionals to prevent 50% of handicaps in young children. Not only can we prevent lifelong suffering but Florida can save over $250 million dollars annually by focusing our efforts on the first sixty months of life including the prenatal years.

Our findings and recommendations are based upon four basic principles.

1. The prenatal years and the first sixty months of life are vulnerable years where the potential for damage and the potential for preventing or minimizing risk conditions is great. Yet these are the very years where the Prevention Task Force found the largest gap in both private and public services.

2. Families are essential to the health and well being of our young, yet today, families of our youngest are at greater risk than any other segment of our population.

3. Risks to young children are cumulative. A low birthweight baby born to a teen who quits school is at great risk.

4. Because risks to infants are cumulative, a continuum of services is needed to ensure that identified high risk children develop their full potential.

In the birth of a child lies a family's and a nation's hope for the future. But, today, that future is in jeopardy because our youngest children are at greater risk for disabilities than ever before.

1. More are growing up in poverty than any other segment of the population. In 1979, 20.4% of Florida's children under age four and 62.5% of children under 2 in female headed households were living below poverty, and these numbers are increasing.

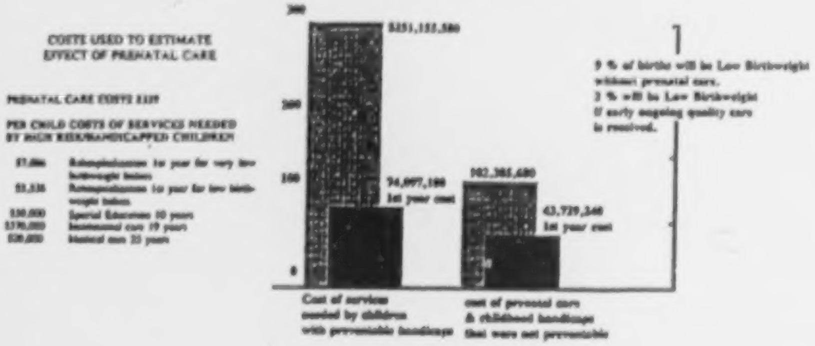
In Gadsden county, Franklin county, and Jefferson county over 40% of all children aged 0 to 4 were growing up below poverty. Here in Pinellas county, 9.39% of individuals were living below federal poverty compared to 17.23% of young children. For these families primary health care is often difficult to get because Medicaid in Florida serves only around 34% of children living below poverty.

2. Most children are born to young families who are just beginning to earn a living. Many have no medical insurance and few back-up resources. The cost of the basic health care needed to ensure a healthy pregnancy and childhood has increased. When complications arise, such as a low birth weight birth or an at risk pregnancy, families can be destroyed.

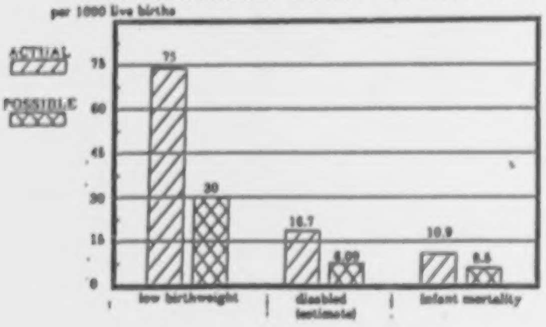
3. In Florida, every 5 hours an infant dies before its 1st birthday, and every 42 minutes a low birthweight baby is born. While reductions in Florida's infant mortality have been dramatic low birthweight has remained at around 7.5% for the last 5 years. We actually have had an increase in the number of sick babies and the severity of their conditions in our neonatal units. This is due to Florida's growth; advances in medical technology which allow us to keep very sick children alive who would not have survived in the past; and an increase in addicted babies and babies whose parents have A.I.D.S. With quality, early, regular prenatal care we could reduce low birthweight by more than 1/2 and save Florida over $148 million dollars in services that will be needed for children with preventable handicaps.

MATERNITY CARE SAVES FLORIDA MONEY

IF 64,000 PREGNANT WOMEN BELOW 150% OF POVERTY RECEIVED QUALITY PRENATAL CARE FROM THEIR FIRST TRIMESTER FLORIDA WOULD SAVE AN ESTIMATED $148 MILLION DOLLARS



ESTIMATED EFFECTS OF PRENATAL CARE FOR ALL WOMEN ON LOW BIRTH WEIGHT DISABILITY & INFANT MORTALITY IN FLORIDA



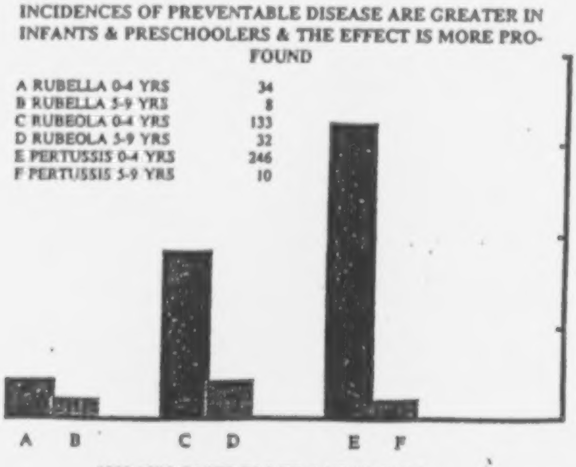
4. This year we collected county data on preschoolers and found that 75,093 children aged 0 to 5 in our state were involved in indicated reports of child abuse. This represents a staggering 8.4% of all 0 to 5 year olds in Florida. Many young children become handicapped due to abuse and many handicapped/at risk children are abused. We found that low birthweight babies are abused at almost four times the rate of normal weight babies and teens babies are abused at an even higher rate.

5. More than 50% of our high risk infants and young children do not get routine check-ups and immunizations. Incidence of preventable diseases in our young are four to two hundred times greater than that of school age children.

Between 1983 and 1985:

Ten cases of pertussis were found in children five to nine years old. 246 cases were found in children aged 0 to 4.

PRESCHOOLERS NEED IMMUNIZATION

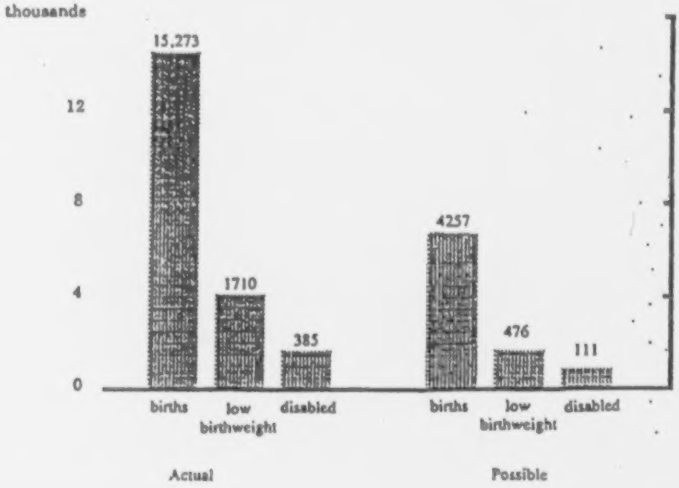


1983-1985 CASES IN 0 TO 4 YEAR OLDS
COMPARED TO CASES IN 5 TO 9 YEAR OLDS

Three hundred and eighty children aged 0 to 4 were reported to have Haemophilus - Meningitus in 1985. One in twenty of these children die and one in four will have permanent brain damage.

6. Every 35 minutes in Florida a baby is born to a child. 15,273 were born to children under age 19 in 1985. Though we have reduced the rate of births to teens from 12% in 1980 to 9.3% in 1985, the absolute number of births to teens increased by 500 last year. Births to children less than 15 years old increased by 123. Teens are at high risk of a low birthweight birth, of repeated pregnancies and dropping out of school. This places two children at risk - the teen and her child.

ESTIMATED EFFECT OF REDUCING TEENAGE PREGNANCY OR LOW BIRTHWEIGHT AND DISABILITIES



1980-85 LIVE BIRTHS TO CHILDREN IN FLORIDA (13)

	015	15	16	17	18	TOTAL TO TEENS 019	TOTAL BIRTHS	% TO TEENS 019
1980	628	1,537	2,913	4,429	6,299	15,806	131,811	12%
1981	603	1,386	2,835	4,501	6,207	15,532	138,521	11.2%
1982	613	1,341	2,834	4,481	6,349	15,618	144,500	10.8%
1983	636	1,361	2,605	4,336	6,153	15,091	149,062	10.1%
1984	547	1,357	2,610	4,211	6,049	14,774	155,344	9.5%
1985	670	1,407	2,709	4,348	6,139	15,273	163,732	9.3%

Risks to families with young children are further stressed by shortages in appropriate services and personnel. This is the real human tragedy because it is the preventable story. I will tell this story as it was told to us at 11 statewide forums.

We learned that the service system was a maze of uncoordinated, often duplicative underfunded programs that made providers and parents frustrated as they attempted to get a child or pregnant women the service supports needed to prevent long term damage.

Medical providers talked of the human and monetary cost in low birthweight babies born to pregnant women who could not afford prenatal care and of the over 8,000 women who walked into hospitals without any prenatal care. Obstetricians spoke of liability rates that are forcing them out of business.

They told us of infants and children waiting in hospitals after medical discharge and given to our state for foster care because we had no parent training of a child, and then sending very sick babies home with scared, frightened parents who do not know how to care for a sick child.

The sad fact is that if a parent with a medically vulnerable child wants their child to get specialized health services, it is better to give that child to the state for care.

Parents and pregnant women unable to afford health care told us of waiting for hours at County Health Units and Children's Medical Service clinics for check-ups, immunizations, or to get help because their child was sick.

The clinics and doctors told us that services to children were underfunded and the reimbursements were different from program to program creating a paperwork nightmare. The Medicaid program reimbursements to professionals for Early Periodic Screening Diagnosis and Treatment (EPSDT), a preventive service, were so low ($10.00) that doctors lost money. Last year this program saved $273 for each child or $23.4 million dollars for all medicaid children aged 0 to 20 who participated in the EPSDT program.

Teen parents told us how vulnerable and frightened they felt and how after their child was born they quit school because there was no day care.

We heard from parents and providers how desperate they felt about little children with high risk handicapping conditions who had to wait until age five for services.

They told us of the quiet desperation that occurs to a family with a medically vulnerable child - how marriages, personal lives, and bankruptcy are almost inevitable when the family decides to keep the child at home.

PREGNANT WOMEN AND HIGH RISK HANDICAPPED CHILDREN CANNOT WAIT FOR HELP. THEIR FAST GROWING MINDS AND BODIES WILL NOT WAIT. IT IS ESSENTIAL THAT AT THE FEDERAL AND STATE LEVEL THAT WE APPROACH THE PROBLEMS OF YOUNG FAMILIES AT RISK WITH COMPREHENSIVE SOLUTIONS.

Our research identified infants and children in our state whose risk conditions could be prevented or ameliorated.

- Infants born too soon or with other risk conditions
- Children born to children less than 18 years old
- Children who did not get regular health check-ups and treatment of risk conditions.
- At risk and handicapped children without therapeutic or developmental intervention.
- Abused and neglected children.

We identified cost effective, efficient programs that saved lives, prevented disabilities and minimized high risk conditions so that young children has a chance to grow to be productive citizens. These were:

- Quality, Early, Regular Maternity Care
- Programs to support teen parents & prevent teen pregnancy
- Health Care for preschool children
- Education and associated services for Handicapped/High Risk Children aged 0 to 4.
- Support Services for families with high risk and disabled preschool children
- Local Planning and Advocacy

Last year with the help of the State Legislature we were able to pass The Handicap Prevention Act of 1986. The act provides the means by which agencies, the Governor, and Legislature can assess the status of prevention services in our state with the intent of gradually funding these services.

This year we have begun to collect county data on these issues and to focus on systemic changes which are needed to help our state prioritize prevention and families rather than crisis intervention.

We thank you for your tireless effort for Florida's infants and young children. The new Medicaid reforms, if adopted by our state, will saves lives and prevent disabilities. We will work hard to have Florida set its Medicaid level up to 100% of poverty for pregnant women and young children.

Florida has already begun to take advantage of Public Law 99-457 which supports mandatory preschool education for handicapped 3 & 4 year olds and provides grants to states for high risk handicapped infants and toddlers.

We would like you to be aware of how some crucial Federal programs are affecting Florida's efforts at prevention.

1. **Block grant funds for programs that prevent and minimize handicaps** have not kept pace with Florida's growth or cost of living increases and we are seriously falling behind in areas such as WIC - the food and nutrition program for pregnant women and young children, and Title V which supports our Maternal and Child Health prenatal care program and programs for medically at risk young children.

2. As Congress reviews the issue of catastrophic funding for the elderly, please do not forget the special and important catastrophic health care needs of families whose children are born with serious medical problems.

3. A home and a family is an absolute need for young infants especially those who are medically vulnerable. Yet, many of our programs do not support these families. If home medical care was the first priority in utilization of medicaid funds for young children, fewer children would be left in hospitals.

4. We all need to work at interagency coordination and case management. We need to fuse this patchwork system of care so that families with young children do not have to go from provider to provider to find services needed to minimize and prevent their disabilities. The Medicaid legislation and preschool education legislation is a good beginning.

5. MANPOWER SHORTAGES are serious in Florida. Even if Florida decides to increase Medicaid eligibility to 100% for pregnant women and young children, we will not be able to serve those who are eligible. A series of reforms are needed including; medicaid reforms, liability and malpractice reforms, and incentives for medical providers to serve in rural or medically underserved areas.

- Only 6% of Florida Obstetricians and Pediatricians will take Medicaid patients.
- 23 counties are without a Medicaid participating obstetrician, 19 counties are without an obstetrician or a nurse midwife, and 22 are without a pediatrician.

We would like you to be aware that the administration has decided to no longer fund scholarships through the National Health Services Corps Program (Public Law 94-484, section 331). Two hundred physicians have been placed in Florida's rural, medically underserved areas. It reimburses newly graduated doctors who participate for their education and has been the backbone of our state's health care in rural areas. Many of these physicians have grown to love their community placement and remained.

In 1986, we were targeted for 81 placements.

In 1987, we are targeted for 12.

In 1989, we are targeted for 1.

By 1990 we will receive 0, if this program is allowed to end. When Florida has only 307 practicing OB's who will take Medicaid, these 200 physicians are critical and important health care providers.

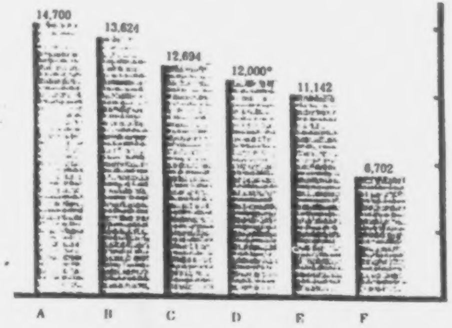
Florida's and this nation's babies and young children deserve a chance for a healthy and productive life. These little ones have been waiting and the cost of waiting for them has become too high. On behalf of them we thank you for your concern. In Florida, they are:

- the 12,342 low birthweight births in 1985
- the 15,273 children born to children less than 18
- the 70,000 who did not get health check-ups
- the 75,000 preschoolers who were abused
- the 10,000 handicapped preschoolers who need special education
- the 21,000 children on waiting lists for day care so their parents can work or finish school, and the
- children born to addicted and sick parents and,
- families with medically vulnerable infants.

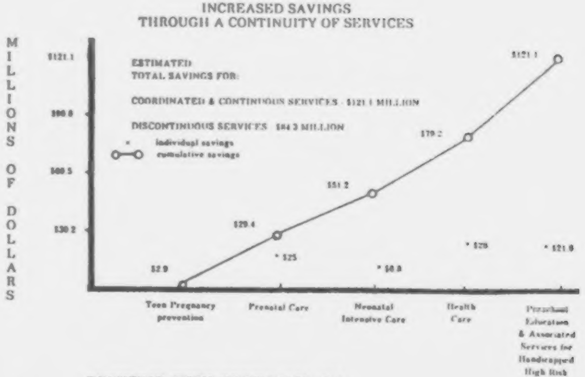
Thank you.

A CONTINUITY OF SERVICES FOR HANDICAPPED/HIGH RISK CHILDREN PREVENTS THE CUMULATIVE AFFECT OF RISK FACTORS & IS COST EFFECTIVE

FLORIDA CAN REDUCE HANDICAPS BY 50% BY TARGETING RISK GROUPS WITH A CONTINUITY OF CARE



SAVINGS ARE CUMULATIVE WHEN SERVICES ARE CONTINUOUS FOR HIGH RISK GROUPS



A. THE # OF CHILDREN BORN IN 1983 EXPECTED TO NEED SPECIAL EDUCATION AND BE IDENTIFIED AS HANDICAPPED.

B. REDUCTION OF BIRTHS TO TEENS BY 75% REDUCES LOW BIRTHS, MORTALITY, AND HANDICAPS.

C. PRENATAL CARE REDUCES LOW BIRTHWEIGHT, INFANT MORTALITY AND HANDICAPS.

D. GRADUATES OF NEONATAL INTENSIVE CARE IN FLORIDA HAVE AN IMPAIRMENT RATE OF 15%. (NATIONALLY IT IS 25% AND PRIOR TO NICU IT WAS 50% FOR LOW BIRTHWEIGHT, SICK NEWBORNS)*. THE FIGURE ABOVE ONLY INCLUDES THE 25% TO 15% DROP CURRENTLY BEING ACHIEVED SINCE EXPECTED DISABILITY HAS BEEN FIGURED ON 25% OF LOW BIRTHWEIGHTS WHO LIVE.

E. HEALTH CARE (EARLY IDENTIFICATION & TREATMENT,. 80% OF HANDICAPS ARE ACQUIRED AFTER BIRTH. THIS REDUCTION ,WAS FIGURED ONLY ON EPSDT ELIGIBLES NOT SERVED SINCE RESEARCH ON REDUCTION RATES IS ONLY AVAILABLE ON MEDICAID ELIGIBLES.

F. EARLY CHILDHOOD EDUCATION FOR HIGH RISK AND HANDICAPPED CHILDREN FIGURES ARE BASED ON THE PERRY PRESCHOOL DATA ON SPECIAL EDUCATION PLACEMENT AVOIDANCE. (35% VS 65% PLACED IN SPECIAL EDUCATION). HANDICAPPED AND HIGH RISK POVERTY CHILDREN, CURRENTLY NOT SERVED, WERE INCLUDED IN THE ESTIMATION.

REDUCING TEEN PREGNANCY BY 75% SAVES APPROXIMATELY 2.9 MILLION DOLLARS ANNUALLY AND REDUCES THE NUMBER OF WOMEN WHO WILL NEED PRENATAL CARE, AND OF CHILDREN WHO WILL NEED HEALTH AND EDUCATIONAL SERVICES.

PRENATAL CARE FOR LOW INCOME WOMEN SAVES APPROXIMATELY 25 MILLION DOLLARS ANNUALLY. 1.5 MILLION IS SAVED IN REDUCED NEED FOR PRENATAL SERVICES TO LOW INCOME TEENS IF TEEN PREGNANCY HAS DECREASED BY 75%.

NEONATAL INTENSIVE CARE (NICU) PRODUCED APPROXIMATELY A $6.8 MILLION ANNUAL SAVINGS IN 1983. IF TEEN PREGNANCY AND PRENATAL CARE PREVENTION PROGRAMS HAD OCCURRED, FLORIDA WOULD HAVE SAVED AN ADDITIONAL $15 MILLION IN REDUCED NICU SERVICES.

HEALTH CARE: EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT PREVENTION COULD SAVE AN ADDITIONAL $28 MILLION IF ALL ELIGIBLE CHILDREN WERE SCREENED.

SPECIAL EDUCATION FOR HANDICAPPED PRESCHOOLERS COULD REAP AN ANNUAL SAVINGS OF AROUND $21 MILLION. IF EARLIER SERVICES REDUCE HANDICAPPING CONDITIONS BY AT LEAST 3668, ANOTHER $20 MILLION IS SAVED ANNUALLY FOR 10 YEARS.

THOUGH THESE ARE ESTIMATES AND CAN NOT BE DEFINITIVE OF THE EXACT MONETARY SAVINGS TO FLORIDA, IT IS CLEAR THAT PREVENTION OF HANDICAPS IN YOUNG CHILDREN IS A WISE INVESTMENT.

PREPARED STATEMENT OF LINDA STONE, Ph.D.

Good morning. My name is Linda Stone. I coordinate psychological services for the Neonatal Followup program at Orlando Regional Medical Center and I chair the Florida Consortium for Newborn Intervention Programs.

I am grateful for the opportunity to present our thoughts on the need for immediate family support and developmental intervention for high risk and handicapped infants. In most instances this means when an infant is admitted to a Regional Perinatal Intensive Care Center's Neonatal Intensive Care Unit (RPICC-NICU). However, with the advent of amniocentesis and ultrasound, family support can begin at the time a problem is detected.

Florida has been a model in this country for delivering quality medical care for high risk obstetrical and neonatal intensive care patients. It has been demonstated by Children's Medical Services' Regional Perinatal Diagnostic and Evaluation Program data that NICU care has greatly reduced the incidence of developmental disabilities in larger infants. Additionally, neonatal medicine has saved larger numbers of low birth weight and other medically vulnerable infants. While Florida has every right to be proud of it's accomlishments in the delivery of widely available perinatal care, this should be viewed as only the beginning. Medical care is just one piece of a prevention continuum aimed at reducing handicaps in young children. In a presentation to the Interagency Council for Infants and Toddlers last week, Dr. Steve Freedman of the Institute for Child Health Policy suggested that development = medical care + education. We would like to expand this equation to read Development = Medical Care + Family Support + Early Intervention.

There were approximately 6000 babies admitted to Florida's RPICC's during 1985-1986 fiscal year. It is well documented (Drillien, 1959 & 1964) that all infants requiring neonatal intensive care are considered to be at risk for developmental handicaps. In addition, most families whose children are admitted to intensive care experience situational (Caplan, 1960; Caplan, Mason and Kaplan, 1965) and other crises. For this reason, all of these families require at least immediate short term crisis intervention and education to enable them to effectively parent their high risk infant. NICU early intervention projects funded by Florida's Developmetal Disabilities Council (D.D.Council) collectively found that:

- 35% of these families require in depth psychosocial support due to complex social situations such as parental substance abuse and/or the inability to provide basic parenting functions due to physical, psychosocial, or economic factors.

- 20% of these infants are extremely vulnerable and require special developmental intervention while hospitalized. Risk factors include low birth weight (less than 3.3 pounds), respiratory problems, asphyxia, central nervous system abnormalities, congential anamolies, sensory impairment as well as surgical, metobolic, and other complex medical problems.
- 42% of these infants and their families are in need of transition services at and after discharge including discharge planning and active follow-up of medical, psychosocial, and educational recommendations.

In 1979, Jackson Memorial Hospital and Orange County Public Schools in conjunction with Orlando Regional Medical Center each received U.S. Department of Education grants for the purpose of developing models of very early intervention designed to prevent or ameliorate handicaps in this population. In addition, Shand's Teaching Hospital was in the process of developing a similar model. These projects clearly demonstated that in those RPICC's providing high quality medical care coupled with appropriate psychosocial and developmetal services, the incidence of family stress and developmetal delays has been significantly reduced as compared to RPICC's providing medical care, only.

The importance of a holistic approach to the care of the high risk and handicapped infant was recognized in 1981 by the D.D. Council. In 1981, five year demonstration grants were awarded to four RPICC's for the purpose of developing or enhancing in-hospital and/or home based early intervention models. Again, it was demonstrated that these local programs were effective secondary prevention measures. The National March of Dimes recognized the importance of these prevention efforts by providing substantial interim financial support.

It has become clear both nationally and in the State of Florida that there is a need for these type of programs. The Pre-kindergarten Study Panel Report (Pre-K Study) commissioned by the State recommends a full continuum of services be made available to high risk and handicapped preschool children, birth to five. Part H of the recently passed Public Law 99-457 provides new funding for states to implement family support and educational services to high risk and handicapped children by 1991. The Prevention Task Force cites the NICU Intervention programs as critical to their recommended continuum prevention services. Yet, unless there is a commitment of State funds, virtually every NICU early intervention program will terminate in June of this year. These programs are consistent with national and state goals and do an excellent job in identifying and providing services to young children at risk for disabilites and their families.

The need for these types of programs for all NICU infants and their families can be most clearly demonstrated by real life case studies.

> Neil's family had recently moved to Florida when his mother delivered him, without much warning, in a bed in a community hospital. She was six and a half months pregnant.
>
> Mr. Jones had just begun a new plumbing business and Mrs. Jones was an early education teacher. The family planned this pregnancy and knew the importance of prenatal care. Neither the obstetrician in the Midwest nor the one in Central Florida had educated Mrs. Jones regarding the signs of premature labor. When Mrs. Jones began to cramp on Sunday, she didn't want to bother the doctor since she was unsure of what it meant and thought it was probably not important.
>
> When she finally phoned, Mrs. Jones' doctor told her that she was having a miscarriage and that there was nothing he could do but speed it along. Her water was broken and she was left alone to see Neil came into the world alive, weighing one and a quarter pounds. Neil was left with his family to die until it became obvious that he had other ideas.
>
> Neil was stabilized and transported to an RPICC by that center's transport team. He was in very critical condition. Before they left, the team gave the family a Polaroid snapshot of Neil, verbal information about the resources of the center and the care he would receive, and written materials describing the NICU and how and when to get in touch with the professionals caring for Neil.
>
> As soon as Neil arrived, the family was contacted by the Neonatal Intervention program family counselor assigned to the case and both parents were encouraged to visit Neil as soon as he was settled. Mr. Jones came to the center within a half hour of this call, clearly upset. Information was provided by the NICU team which included the neonatalogist in charge, the nurse and respiratory therpist caring for Neil, and the family counselor. Medical and emotional issues were slowly and concisely addressed, as they would

be again and again over the ensuing weeks and months to one or both parents.

As can be guessed, Neil's birth coupled with the rocky hospital course of a very premature infant pushed his parents onto an emotional roller coaster. They vacillated from wishing that he would die because they feared massive brain damage to fearing death because they had unwittingly become attached to him. Each time there seemed reason for optomism, there would be a setback.

Neil's parents would receive in depth individual counseling, education regarding neonatal intensive problems and their treatment, education on premature infant development and special needs, and peer support from a member of the NICU parent support group. Neil developed a chronic lung condition requiring him to be handled in a special way while in the hospital and at home. Therefore, extensive in-hospital interventions and discharge planning were required. Multidisciplinary family care rounds and developmental care rounds were held to plan Neil's treatment and the support his family would need to implement it. This entire process was facilitated by the in-hospital NICU Intervention personnel.

Discharge usually precipitates as much of a crisis as does admission. Parents have difficulty envisioning themselves as able to take over the functions of a highly sophisticated NICU staff. This fear is usually magnified when a child goes home with special equipment such as oxygen and an apnea monitor, as did Neil. For infants like this and other high risk infants, home support becomes essential. The community in which the Jones lived had a waiting list for early intervention services and these services were center based. They needed services right away and they had to be home based. The services also had to help the Jones begin to manage their son's multiple medical and educational needs. Neil and his parents were lucky. The hospital also had a home based NICU Intervention program which would provide personnel to work with the family at home beginning right after discharge. The infant educator would continue to provide the parent support, parent education, and infant intervention necessary to enable the Jones to satisfactorily parent and advocate on behalf of their son.

> Neil had a rough first year. He was rehospitalized four times with repiratory problems. His parents became frantic, at times, but knew how and where to seek support before a crisis set in. He received community based early intervention and therapy when he was well enough to participate. This transition was facilitated by his infant educator who helped direct his parents.
>
> Neil is now four and participating in a regular nursery program. While he is evidencing a language delay, it appears that his intelligence in within normal limits and that he will achieve school and occupational success. He has a new sister who is nine months old. With his sister, his mother again experienced premature labor, but with the appropriate guidelines she was able to deliver a healthy, full term infant. If you ask the Jones, they will tell you that they are eternally grateful that the NICU where their infant was admitted had an in-hospital and homebased intervention and support program.

The preceding case study emphasizes the plight of parents who experience the birth of a premature or sick newborn. Let us now look at the effects of high risk birth from the infant's perspective.

> David was born at 29 weeks gestation (40 weeks is term) in an outlying hospital without maternity facilities. His mother, Tracey, was fifteen years old. She had only acknowledged her pregnancy two weeks prior and still had a month to go before she could be seen at the health department.
>
> David was given oxygen in the emergency room using a rubber catheter, as no better equipment or expertise was available. He arrived at the NICU very bruised and with a lengthy admitting diagnosis common to preterm infants. Light levels were intense and noise levels were almost deafening to his very immature nervous system. What's more, the noise and light were the same day and night. Life saving medical procedures were painful and there was little or no time for David to recover from one when another began. Each new procedure compromised his breathing or heart rate and caused him to change color. Little energy was available to make contact with people and when contact was made, it often hurt.
>
> David's recovery was very slow. His airway had been scarred by the respirator tube used to aid

> his breathing. At two months of life, his airway closed and his breathing stopped. He was resuscitated twice and a tracheostomy had to be performed. This exhaused whatever enery reserves he had stored and he again had to be fed intravenously. Every time he was touched, he turned blue, scaring experienced medical staff, not to speak of his mother and grandmother.
>
> When she found out she was pregnant, David's mother decided that she would put the baby up for adoption. Her own mother was single and unemployed. Neither Tracey nor her mother had the resources to care for another person. Visits to David were infrequent and when they occured they were extremely upsetting. In addition to the trachestomy, he also required a shunt to control hydrocephalus caused by a massive brain bleed, not uncommon in premature infants. David was very fragile, unresponsive, and required a great amount of care. The question was who would want to adopt him and if he was unadoptable, how could Tracey and her mother care for him at home?

While they obviously do not have all the answers, Neonatal Intervention Projects are beginning to address the issues confronting infants born at risk. Intervention staff help medical staff pay attention to the intensity and duration of light in nurseries, helping to screen isolettes and turn lights off to approximate more normal conditions. Noise levels are monitored and ways are found to reduce the amount of noise coming into the isolette. Quiet periods are becoming part of nursery protocol. Emphasis is placed on the fragile status of the premature and sick infant's nervous system. Parents and staff are taught to read infant cues and to time procedures and care so that they are minimally stressing.

Special developmental nurseries are being set up to meet the needs of the chronically ill infant requiring long periods of hospitalization. Special interdisciplinary care plans are developed and implemented by hospital staff and the child's parents. The goal of these plans is the smooth transition of the the child's care from staff to parent and from hospital to home. Attention is paid not only to the child's medical and caretaking needs, but his changing developmental needs, as well. Parents take these children home with the support and confidence necessary to integrate the child into the family unit and to help make them be all they can be.

Neonatal Intervention programs have two major goals. The first is to provide a more comprehensive care base for the high risk neonate and his family with the intent of ameliorating to the maximum degree possible the adverse sequelae of early problems. The second goal is to insure that appropriate supportive services are provided as quickly as possible, given the availability of resources. These programs include screening, identification, and developmental followup for high risk infants and their families. They also provide service coordination to include in-hospital case management, discharge planning, and home based early intervention. A bill will be presented to the Florida Legislature during this session asking for these services be funded and made available statewide.

Parent-to-Parent of Florida, the project that sponsered this conference, works under the assumption that it is an adult function to be responsible for a child, regardless of that child's status. This project recognizes that with a high risk or handicapped child, this function cannot be carried out by parents in isolation. Parent-to-Parent also recognizes that the professionals working with these children come and go. Parents of handicapped children must be educated to support and advocate on behalf of their children with the goal of fostering independence to the extent possible and to produce children who are productive citizens of our communities.

DRAFT 1

Testimony of

Steven M. Scott M.D.

before

Senator Lawton Chiles

Howard Johnson Plaza

Tampa, Florida

March 21, 1987

Good Morning Senator.

I am Dr. Steven M. Scott, President of Coastal Group Inc., a physician contract group based in Durham, North Carolina. We provide emergency physicians and obstetricians under contract mostly to hospitals. With me today is Dr. Harvey Gardy who is a Regional Medical Officer with our company and Mr. Dan Lewis who is our marketing officer for Florida based in Jacksonville. We are pleased with the attention your hearing is giving to the subject of neonatal and infant mortality.

An affiliated company, Coastal Emergency Services, Inc. provides physicians for the emergency departments of about 190 hospitals including 14 hospitals in Florida. One of the hospitals we serve is Broward General Medical Center in Ft. Lauderdale where we see 80,000 emergency patients annually.

Private practicing obstetricians are increasingly reluctant to attend indigent or otherwise unassigned obstetrical and gynecological patients because of very high malpractice risks and minimal payments for such services. Broward General Medical Center in Ft. Lauderdale experienced some difficulty in assuring proper OB-GYN care and coverage for these patients in 1983. At their specific request, we recruited a group of residency trained obstetricians. Since July, 1983, we have provided 24 hour OB-GYN physician care in the hospital through an affiliated company, Sunlife OB/GYN Services, Inc. Our physicians attended over 4,000 deliveries last year at Broward General alone in addition to gynecological surgery and prenatal and post natal care.

Dr. Gardy directs our services in Florida and is based at Broward General Medical Center. Both of us are licensed in Florida, residency trained in OB/GYN and board certified by the exclusively on patients who are not assigned to private patients.

Malpractice liability

Infant Mortality

Neonatal Mortality

Cocaine Babies

Aids Babies

We have received favorable performance reviews by our client hospitals and medical staffs and we are pleased with the quality of care we have provided. Many additional hospitals and governments are interested in improving the quality of obstetrical and gynecological care for unassigned patients but funding is clearly limiting the more rapid expansion of such programs. We certainly appreciate the interest you have shown in this very important area of care by holding this hearing.

Should you feel we can be of assistance to you as you continue your study of this most important area, I hope you will let one of us know. I would be pleased to address any questions you may have either now or later. Thank you.

Florida contact:

J. Dan Lewis, Jr.
Vice President
Sunlife OB/GYN Services
P.O. Box 5732
Jacksonville, FL 32247-5732

904/399-1279 (Florida)
800/334-3306 (U.S.)

PREPARED STATEMENT OF JON MILLS

The State of Florida is spending nearly 2 billion dollars annually for health care services to low income persons, for significant health care needs in our state are still not being met. One of every 12 Floridians, or one million persons, has inadequate health insurance or no insurance at all. This lack of availability of routine health care coverage has forced many of our citizens to postpone primary and preventive health care until their conditions worsen to the point where hospitalization is needed. As a result, Florida hospitals will lose nearly one billion dollars this year in uncompensated care. Unfortunately, it is the teaching hospitals and government-owned facilities—those institutions which provide the bulk of indigent care—which are being hit the hardest by uncompensated care. If nothing is done, some of these very public spirited facilities may be forced to close.

Another manifestation of Florida's inadequate public health care system is our high infant mortality rate. Although our infant mortality rate has been declining in recent years, it is still above the U.S. rate. And as Senator Chiles knows, the U.S. rate has just fallen from 16th to 22nd on the list of all developed nations in the world, behind such places as Hong Kong and Singapore.

Florida's infant mortality rate is twice as high for black as it is for white infants, and there are still counties in Florida, both urban and rural, where the black infant death rate is 2½ times the white rate.

A recent and alarming development we are experiencing involves the disenfranchising of the near poor, especially pregnant women, from the private health care market. Due in part to skyrocketing malpractice premiums, private obstetrical care now costs over $1,600 in Florida. Add to this another $1,500 in hospital bills—and it is easy to see why many young couples are unable to participate in the private health care market. As a result, pregnant women are seeking care later in their pregnancies, which is one of the major contributors to low birth weight babies.

Florida's health care delivery problems for our low income citizens are serious and require immediate attention. This is why health care reforms are one of the major items on my agenda for Florida's approaching legislative session. There is much to be done in Florida, and there is much you can do at the federal level to help us accomplish our goals. Let me take just a few minutes to describe our plan to you and discuss how you can help.

In designing our plan, we had five major objectives in mind. They are to:

more equitably distribute among hospitals the burden of providing uncompensated care to indigent persons;

shift the reliance on restrictive and costly institutional care to less costly primary outpatient and preventive care;

expand existing programs such as Medicaid to cover a larger number of those most in need;

target resources to those groups such as pregnant women and children where early intervention has the greatest potential for reducing more costly and serious disease; and

create incentives for physicians and other health care providers to participate in the Medicaid program.

The Florida Legislature partially addressed the first of these objectives in 1984 with the passage of the Health Care Access Act which created the Public Medical Assistance Trust Fund (PMATF). This fund was intended to equitably distribute the burden of providing indigent care among all hospitals by requiring hospitals to contribute a percentage of their net revenues to the fund. The fund was then to be used as matching dollars for a new Medicaid medically needy program—a program which we were told would serve 178,000 new eligibles. But unfortunately, the paperwork associated with the Medicaid medically needy program is so massive, the program has been able to serve only a small fraction of those we expected. As a result, a substantial surplus has occurred in the PMATF—causing an even greater financial hardship on the hospitals which the fund was designed to assist.

I will be proposing to the Florida Legislature that we continue in our efforts to make Medicaid medically needy work, and in the meantime that we redistribute on a formula basis the surplus funds in the PMATF to those hospitals with the greatest indigent care burdens. You can assist Florida by reducing the amount of paperwork associated with medically needy, most of which we are told is required by the federal government.

Besides continuing to work on medically needy, we will be proposing expanding Medicaid coverage to pregnant women and children up to the federal poverty level. This new SOBRA option is very exciting to us in Florida, because it will allow us to essentially triple the income level of women who may participate in the program, permitting us to serve some 30,000 additional women and 55,000 additional children with our Medicaid program.

We are so excited about this new option that I will be proposing a companion state program to SOBRA which will serve children from age 5 (where SOBRA leaves off) to age 10. This program will serve just over 100,000 children in our state.

I am also proposing that Florida take advantage of the new SOBRA option of expanding Medicaid services to elderly and disabled adults to the federal poverty level. It appears as though both the Florida Senate and our new Governor are supportive of these new SOBRA options so I believe the prospects for their enactment in Florida are excellent. Let me take this opportunity to encourage this type of flexibility in other areas of the Medicaid program. If the states had the option of expanding Medicaid to low income single males or childless couples, without also expanding AFDC coverage, I feel certain that many states would pursue this option.

Besides expanding the number of persons who will be eligible for the Medicaid program, I will also be proposing that Medicaid physician fees in Florida be substantially increased and in some cases even doubled. For example, the current Medicaid payment schedule to an obstetrician for prenatal care, delivery and postpartum care is only $315 and extensive paperwork is required in order for the physician to be paid. A private paying patient would pay from $1100 to $2500 for the same services. It is little wonder then that only about 6 percent of the state's OB's currently participate in Medicaid, and many of these physicians are pulling out of the program. Clearly, incentives are needed to attract physicians to participate in Medicaid, in the form of both increased reimbursement and reduced paperwork. Again, you can assist us through reducing the massive paperwork associated with Medicaid physician billing.

A final area in which I will be proposing reforms in the Health care system is in increased availability of primary care services. Included in the "'Health Care Access Act of 1984" which I mentioned earlier was a $10 million annual appropriation to establish primary care programs in 18 of Florida's 67 counties. These programs have been very successful at prevening illness and reducing unnecessary hospitalization. Many of the unfunded counties have expressed an intense interest in starting similar programs. For an additional $20 million annually, we can extend primary care services to all 67 of Florida's counties and to an additional 100,000 Floridians. There are federally funded primary care programs in Florida, but additional federal funds for primary care would be very welcome.

In summary, our health care delivery system is changing rapidly as a result of increased competition and steadily rising health care costs. This, linked with the high number of service, seasonal and part-time workers in Florida, is triggering a crisis for the poor and near poor in Florida. Federal, State and local governments have an obligation to ensure that no one is denied access to basic health care services. You have assisted in this process greatly through the creation of new SOBRA eligible groups and applaud your efforts. For Florida's part, we intend to take full advantage of these SOBRA options, and to design other health care programs which meet our individual needs. We hope that Congress will continue the trend of giving states more flexibility in the design of our Medicaid programs, especially the option of expanding Medicaid eligibility to previously uncovered groups. We also plead with you to find ways to reduce the amounts of paperwork associated with eligibility determination and provider reimbursement in Medicaid.

If Congress and the states continue to work together. I have no doubt but that we can have a significant impact on solving our health care problems. Thank you for inviting me to speak to you today and for your kind attention.

INFANT HEALTH DATA
State of Florida
1983

	Hardee County	Highlands County	Florida
Infant mortality rates per 1,000 live births	18.8	14.0	12.2
Neonatal death rates per 1,000 live births (Birth to 28 days)	8.1	11.2	7.7
% total births with low birthweight (under 2500 grams)	9.5%	8.3%	7.5%

Source: 1985 District VI Health Plan, prepared by the Health Council of West Central Florida, Inc.

LETTERS SENT TO SENATOR CHILES FROM CONCERNED CITIZENS

Name: Kerry and Melodee Barnes.
Address: 511-A SE 5 Place, Cape Coral, FL. 33904.
Telephone: (813) 772-8891.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Jason was born 11-1-84 with mylomeningescile—the worst form of spina bifida plus Hydrocephalus (water on the brain) the first week of Jason's life cost over $30,000.00. Jason required another surgery six months later to the cost of $3-4,000. Jason is catherized every 4 hours each day, takes medicine 5 times a day, has physical and developmental therapy 10-12 times a month, is seen by doctors quarterly and will need braces and wheelchairs throughout his life. Jason is our gift from God! and we would have it no other way. Unfortunately we went from having a home and 2 cars with over $22,000 annual income down to 1 car, rented housing and less than $11,000 annual income. We had to file bankruptcy in order to get on with our lives. Please, please, please don't forget us in the Budget, we need help badly!

Thank you,

MELODEE BARNES.

Name: Max E. Bear.
Address: 1902 E. Moreno St., Pensacola, FL 32503.
Telephone: (904) 438-9207.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

One can easily understand the need for an organization like Parent-to-Parent, whose principal focus is to give parents of developmentally disabled children the skills needed to cope with this difficult situation. But the converse of this situation also merits consideration.

What happens, for example, when developmentally disabled parents give birth to and rear children who are not disabled? Do these children need coping skills too?

Admittedly, I don't know how prevalent this situation is; but one would think that these non-disabled children deserve the same kind of assistance that parents are striving to give each other in this kind of organization.

Of course, there is a fundamental difference in the two groups: While parents can be expected to provide peer support and succor, the guidance for coping skills in children would need to come from an instructional source, not from a peer group. But the basic issue remains very similar: Both sets of non-disabled persons—I deliberately eschew the use of the term, "normal"—need and deserve tools to help them handle situations that are different.

Clearly, there is a need to study the problem in depth in order to ascertain how many children, nationwide, we are talking about. Only then can we start devising programs that would be appropriate.

Perhaps a personal reference is fitting here. I happen to be a cerebral palsied father [1] of a son who is thirty-five and a daughter who is twenty-eight. Both are non-disabled. I am proud and gratified that they respond to the love and care their mother and I gave them in the tender years and we enjoy both their affection and esteem. Despite this personal happiness, I recognize that this situation has potential needs as outlined above. If the problem is of sufficient magnitude, I respectfully suggest appropriate remedies and programs be devised.

MAX BEAR.

Name: Steve Beaver.
Address: 1632 Gardner Dr., Lutz, FL 33549.
Telephone: (813) 949-5956.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.

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[1] My wife is disabled, but not DD.

3. Research/Other: no.

Senator Chiles, my daughter Stephanie was born 5 years ago with spina bifida. In her short time in her life she has had 4 major operations due to her birth defect at a cost of well over 65 thousand dollars. We also never know when something else related to her birth defect might happen. This has been a tremendous financial and emotional affect on myself and my wife. My family and I are presently involved with the Spina Bifida Association of Tampa. We as parents of spina bifida children greatly need your support to get the help these children need to be the best they can be in life. Thank you very much.

STEVE BEAVER.

Name: Barbara Behrens.
Address: 9348 90 Terrace N., Seminole, FL 33543.
Telephone: (813) 391-6759 (h), 893-8645 (w).
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My son was born 20 years ago with Spina Bifida. After the surgery to close his back, he needed nuerosurgery to prevent the effects of hydrocephalus. Although insurance helped, it took 2 years to pay the neurosurgeon. Since we were too "rich" for CMS, expenses for shoes, braces, incontinent supplies, and time lost from work have been a constant drain on family resources. At present time he does not qualify for SSI assistance while attending college. An education for him is essential for employment but there are no federal programs that can help him.

BARBARA BEHRENS.

Name: Harriet C. Bennett.
Address: 5700 54th Ave. N. (office), St. Petersburg, FL 33709. Home: 16006 Honeysuckle Pl., Tampa, FL 33624.
Telephone: (813) 223-5383.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: no.

A small segment of Florida's disabled citizens are being helped by the Family Placement Program. The program allows the mentally retarded person (who may also be physically incapacitated) to live at home and be cared for by a relative, rather than be placed in a group home or other state funded facility. The program is apparently cost effective, and is certainly the best environment for many of our handicapped citizens. However, the program is quite small, and additional funding would allow more families to participate in this very worthwhile program.

HARRIET C. BENNETT, ACSW, LCSW.

Name: Particia A. Blake-Hairston.
Address: 455 Palm Street, New Smyrna Beach, FL.
Telephone: (904) 428-9775.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other: no.

Senator, let me congratulate you on the survey that you are conducting. I would like to contribute just a brief listing on concerns of mine as an occupational therapist in the school system and a parent of a child in the system.

(1) The handicapped child is seen 1 x per week for 30 wks. This is not enough. To be more effective each period should be 45 min. sessions for at least 2 sessions a week. Once therapy starts with gross motor activities which is the foundation for building finer motor skills, the child has little time left for table (fine motor) development (usually the main concern).

(2) The children need to be seen the year round, creating a need for summer therapy programs. Transportation remains a problem and an expense.

(3) Coordination of services such as children medical services and Human Resources Dept. should be better organized. Children have been given wheel chairs

that need repair or retirement. These chairs have collapsed with the child in them. There are problems with long waiting periods for equipment that is needed also.

Personal experiences.—

(1) More summer school programs should be scheduled for all children. My son, who is barely passing in science and math is not eligible for summer school. The counselor and teacher states that he is not eligible for summer school.

(2) Salaries of school personnel—Line teachers, physical & occupational therapists and aides—not administrators—should be closely studied in each county. Why is there such a discrepancy throughout the state? These individuals hold the future in their hands. More money is needed to go directly into the hands of these very dissatisfied individuals especially in Volusia County. We are losing highly qualified individuals because of poor, poor monetary reward.

I would be glad to elaborate even more on these issues if needed.

Thank you for this opportunity.

PATRICIA A. BLAKE-HAIRSTON.

Name: Mrs. J. Reed Bradford.
Address: 1121 Hillcrest Drive NE., Winter Haven, FL. 33881.
Telephone: (813) 299-5759.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I am the parent of an 18-year-old man with Spina Bifida. When Tom was born I had never heard of this condition—and most of the parents of people with Spina Bifida that I have met had the same experience. Inroads in the past eighteen years toward public awareness have been tremendous, but there is still much to be done so that people with Spina Bifida will be understood as capable people, with disabilities but able nevertheless to lead productive lives in which they take control of their own destiny. Tom has been "mainstreamed" and done very well, now getting ready to graduate from high school and attend college to study history, and, hopefully, to be a lawyer. Government interests him tremendously, and his father and I would not be surprised to find him in the political arena someday. When that happens, I expect he will be working toward enabling goals for people with handicaps—expanding training programs so that they can go to work in meaningful vocations, thereby becoming taxpayers and not tax takers. There is also the critical need for affordable health and life insurance as these people have extraordinary medical needs. As it now stands, Tom has the option, after he leaves the umbrella of our insurance, of going to work for someone with a good group plan that has no prexisting conditions clause or staying "disabled" to get medicare benefits, thereby not working and being a drain on society—a difficult situation for someone who wants to practice law where it might be difficult to find a firm with such a group plan, or who might want to be in business for himself.

There have been remarkable medical advances over the last eighteen years enabling an improved and longer life for people with handicaps. Society has also moved to integrate these people, through improvement in the elimination of architectural barriers and through attitudinal acceptance of them. Tom longs, however, and so do we, for the day when people with handicaps will not be considered as a group requiring labels, but as individuals with the same mix of hopes and aspirations as the rest of society.

MARJORIE H. BRADFORD.

Name: Norma Bruce.
Address: 214 Sierra Pines Blvd., Lutz, FL 33549.
Telephone: (813) 920-6138.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: no.

As a neonatal intensive care nurse of 10 years, I have been fully aware of the importance of good prenatal—preventive care.

During the last two years, I have been employed in a rural health care clinic that cares for OB as well as general care patients. In mid-February of this year, our obstetrician left our services—due to overwork and lack of funding for an additional OB physician and/or lack of community medical assistance. He was exhausted.

In our area, Pasco County, virtually no alternative has been offered—other than to provide delivery service from a Hillsborough County OB group to the few (39) remaining patients left on our service. There is *no* OB service offered to east and mid Pasco patients at this time in our county!

Prenatal patients are without care. A minute few have sought care in Ruskin at another clinic—a drive of 45 miles. This is an unattainable goal for most low income patients. Our Medicaid dollars are spent transporting those few who qualify to this care. These, of course, are not registered at any hospital for delivery.

Now, after years of encouraging and educating the public in the importance of preventive prenatal care, *we don't have it.*

The infant morbidity rate, maternal morbidity rate, and infant mortality rate are on the rise. We see it weekly in our own area.

Not one of our county political stalwarts are willing to attempt obtaining assistance or bring attention to this grave situation.

NORMA BRUCE.

Name: Kenneth and Sandra Burke.
Address: 7006 Fern Court, Tampa, FL 33634.
Telephone: (813) 886-6498.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

We as parents of two children born with the birth defect spina bifida have had to change our lifestyle drastically to accommodate the problems associated with this birth defect. We were not allowed out of our own feelings and responsibility to these children to have a "normal lifestyle". The cost to raise and maintain children with this problem even though health insurance was provided, the 20% for our part did place a burden upon the family. Even as these children grow older, the problem never goes away, it just changes to something else.

KENNETH E. BURKE.

Name: Mary Ellen Byrne.
Address: 3330 Wilkinson Rd., Sarasota, FL 33581.
Telephone: (813) 488-6714.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: yes.

I am currently a teacher of Preschool Variant Exceptionality class. Over the past 12 years I have worked with the 3-5 year old population. It has been my experience that out of 10 students a year in my class 2 to 4 of them at the end of 2-5 years of early intervention enter kindergarten with little or no support. This results in a tremendous saving for the cost of education. That savings to society could be maximized if early intervention was provided to the 0-2 year old population. Funding needs to be structured to allow services to be given to families in a variety of service deliveries methods. Flexibility in funding needs to be structured to encourage interagency cooperation.

MARY ELLEN BYRNE.

Name: Mary Ellen Byrne, President, DEC 71. Federation.
Address: 3330 Wilkinson Rd., Sarasota, FL 33581.
Telephone: (813) 488-6714 or 924-8336.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: yes.

Attached is a statement from the Division of Early Childhood, Florida Federation, Council for Exceptional Children representing parents and practitioners throughout the State. We are an organization dedicated to promoting early intervention, education and research involving young children. We provide information and direction, priorities to issues concerning young children.

[The statement follows:]

I am speaking on behalf of the Council for Exceptional Children Division of Early Childhood. We are part of the Florida Federation of this national organization of parents and practitioners. Our organization would like to urge you, Senator Chiles, and your colleagues in Washington to support the 1986 amendments of P.L. 99-457 and P.L. 99-372. These amendments to 20 USC Section 1400-1485 are a strong start in implementing comprehensive early intervention services to very young handicapped and "at risk" children.

There is a critical need for services beginning at birth for handicapped infants and toddlers, as well as their families. With comprehensive cooperative and multidisciplinary services, the potential for developmental delays and severe handicapping conditions can be minimized. These services must be a coordinated interagency effort which include: prenatal care, preventative health care as well as medical intervention, needed therapies, diagnostic and family support services as well as education and training for children, parents, and professionals.

The Education for all Handicapped Children and the Handicapped Children's Protection Act are specific in their intent, findings and policy. However, without the appropriate and critically needed levels of funding they are simply an impressive collection of words. The services can be provided at the national, state, and local levels with adequate funds. They can help reduce educational costs to our society by reducing the need for special education and related services once these infants and toddlers reach school age. They can also assist in providing families with the types of support needed to cope with a handicapped individual—thereby minimizing the need for institutionalization at a later age.

We ask you to support and to encourage others to support, full and multiple year funding for Early Intervention Services to handicapped and "at risk" young children.

Thank you.

MARY ELLEN BYRNE,
President, Florida Federation, Division of Early Childhood,
Council for Exceptional Children.

Name: Della Casey.
Address: 630 SW 68 Terr., Pembroke Pines, FL 33023.
Telephone: (305) 981-7068.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My granddaughter is a Trisomy 18 child—she will be 4 years old in May. She has numerous medical and physical problems. The only assistance my daughter receives is the preschool program—I help as much as I can but she needs help with medical expenses. So far she "falls through the cracks" of the assistance programs.

We manage OK now, but are unable to afford medical insurance, due to the preexisting problem. Special consideration needs to be taken to assist families when they are caught in a medical dilemma such as my daughter.

"Some of the stories I heard in Tampa at the "Parent to Parent" meeting were like tales from the "Dark Ages".

DELLA M. CASEY.

Name: Sara Ciccarello.
Address: 709 E. Broad St. Apt. A, Tampa, FL 33604.
Telephone: (813) 237-5344.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My son Peter Ciccarello is 9 years and he was born with Spina Bifida (open spine). He had approximately 6 to 8 surgeries in the first 2 months of his life and more since than. His medical bills, not counting his pediatrician, for the first year of his life was more than $50,000. He has had at least one or two surgeries almost every year since and countless tests, office visits, etc.

Please help us. Thank you very much.

SARA J. CICCARELLO.

Name: Sandra E. Coleman.
Address: 2350 Oriole Dr., St. Cloud, FL 32769.
Telephone: (305) 892-9864.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I am a parent of a 17 month old Down syndrome son. I have problems finding local services for my son. I have to travel 106 miles round trip to find therapy for him. Our children are bused to the next County which is Orange for schooling. I work full time and there is only one place that I could find in Orange, (nothing in Osceola), that would provide child care and therapy before the age of 5 years. I understand now there is a waiting list. What do these parents do if they must work? U.C.D. of Orlando have provided a wonderful service, but unfortunately they don't have enough money or space to expand. Osceola County needs services like this so desperately.

I also have problems with insurance companies, they won't pay for therapies needed over with referrals and prescriptions. Prudential just gives me a runaround and Cigna which is a HMO states in their contract that they will only pay for 2 months physical therapy per condition.

They won't even consider occupational and speech. They told me I knew what the contract read before I signed it. How was I to know I was going to give birth to a handicapped child? How can they say they are setting the standards for excellence when they discriminate against handicapped children. I feel this policy puts a great deal of strain on the state. They told me the state would help me! Please check into these HMO insurance companies. The doctor I had was good, he tried many times to get coverage for me but was unsuccessful. He was the chief on the staff. He eventually quit and went back to private practice. They are a racket.

They say they are cost effective! Only to themselves not for the state.

If we parents who work and have insurance should at least be able to get the coverage so we won't have to ask the state to help.

We were not a preexisting condition!

SANDRA E. COLEMAN.

Name: Mr. and Mrs. Steven Culliton.
Address: 100-46 Street South, St. Petersburg, FL 33711.
Telephone: (813) 321-3841.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Dear Sir, we have a daughter, her name is Alissa Nicole. She is 2 years old on Feb. 27. She was born with Spina Bifida. Her first month of life cost about $40,000 for her hospital, surgeries. Last year she had to have a shunt revision we didn't expect and that cost about $6,000.00. She has five doctors she sees every six months. She is not our only child either. We also have a 6 year old boy. We are asking for any possible help you can give us. We've gone from one agency to another and no one seems to have any funds for Spina Bifida.

Thank you,

STEVEN CULLITON.

Name: Susan Drexler.
Address: 130 Higgs Dr., N.E., Pt. Charlotte, FL 33952.
Telephone: (813) 629-3805.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My child was born 11 mos. ago and was diagnosed as having Cornelia DeLange Syndrome. She spent 1 mo. in Shands Hospital. We carry our own private insurance at a cost of over $300 a mo. Since our child was born, our premium per mo. has increased by $50. I have 3 other children. We have been offered no help in the costs not covered by our insurance (i.e., $500 deductible, 20% of 1st $5,000, & of course, whatever costs over & above what our insurance company considers 'fair & reasonable'.) It has been a fight getting the services needed for Mandy. I am still trying to ascertain speech therapy. We have a $1,000,000.00 life-time ceiling on our insurance for Mandy & I worry daily what we'll do if when that is used up. We already have been spending on our own over $100 a month on special bandages and $30-40 a week on special formula. These are not covered by our insurance, because they can be bought over the counter. We are probably lower middle class and a family of six. I feel we could use family counseling right now to just help us cope with the family stress involved with having a baby with ongoing problems & permanent disabilities. I really hope our family can make it intact as a family unit. But for us, right now, counseling is too expensive.

Thank you for reading this & for being here with us.

SUSAN DREXLER.

Name: Kelly Drumm.
Address: 502 S. Everina, Cir., Brandon, FL. 33511.
Telephone: (813) 685-7288.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Kelly has had several thousands of dollars spent on operations and hospital stays, Doctor's fee and medicine.

A lot of company insurance plan's do not pay for this type of birth defect and life insurance is hard to come by at a rate that can be affordable.

People with or parents with Spina Bifida need help. Kelly has spent about 2 years in a hospital in her 15 years.

ED AND PEGGY DRUMM.

Name: Mary T. Dunlop.
Address: 170 Roberta Rd., Ormand Beach, FL.
Telephone: (904) 441-8627.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: no.

I have been working as a social worker in Florida for the past 2 years. First in developmental services, currently at Volusia/Flagler Easter Seals.

Easter Seals is the only Early Intervention Service in the area. Some people have to drive 30 or more miles to receive therapy. Many of our clients are young, low income clients and have problems even getting across town with a severely handicapped child. I would like to see some travel assistance provided. I also am concerned with the eligibility requirements for HRS Developmental Services funding. I have seen many delayed children who do not meet requirements for services.

MARY T. DUNLOP.

Name: Barbara Jo Finer.
Address: 4920 West Blvd. Naples, FL 33940.
Telephone: (813) Work 262-7302.
The testimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: No.
3. Research/Other: No.

As a working single mother of a 2½ year old child with hypotonia (low muscle tone) and developmental delays in gross motor, fine motor, language and adaptive skills, I have become acutely aware of the pressures placed on a working parent when support facilities are lacking. I have missed substantial amounts of time from work in order to attend to the medical needs of my child. I also learned when I was forced to change jobs that may child was uninsurable for medical coverage—a problem which I am sure the majority of parents face.

I now have to contend with divorce laws which do not place requirements on a non-custodial parent to provide for a child who has reached the age of majority—even though my child my need care and special education well into his adult years.

BARBARA JO FINER.

Name: Linda Friedman—Miami—Dade County, Human Rights Advocacy Committee—Chairperson, Developmental Services.

Address: 2121 Jackson St. #28, Hollywood, FL.

Telephone: (305) 923-6296. Work: (305) 547-6961.

The testimony written below represents:

1. Personal experience in my family: No.
2. Work related experience: Yes.
3. Research/Other: No.

I am particularly concerned about the growing problem of children getting caught in a political/monetary battle between HRS Developmental Services and HRS Children Youth and Family Services. When a child is adjudicated dependent almost from birth and has medical/developmental problems that initially require hospitalization, the child often gets lost in the system and ends up growing up in the hospital. CYF can only provide foster care services at a relatively low medical rate that is not accepted by most specialized care facilities. D.S. says that they are not providing residential services to infants. I am presently aware of at least 9 children (infants) that are literally being raised at Jackson Memorial Hospital with no where to go. Some of these infants have been in the hospital since they were born and now they are almost 2 years old and medically stable, ready to leave the hospital. This appears to be an on-going problem with no resolution in sight. While the 2 departments of HRS decide who is responsible and what needs to be done, the babies are suffering. I am writing as a concerned citizen and advocate for these babies.

LINDA FRIEDMAN.

Name: Marge Gibbons.

Address: 15001 Sovereign Dr., Largo, FL 33544.

Telephone: (813) 595-0118.

The testimony written below represents:

1. Personal experience in my family: No.
2. Work related experience: Yes.
3. Research/Other: No.

As a professional for many years, I have been involved in hundreds of meetings with parents. Through the years, with the proliferation of paperwork and rules and regulations, I have seen a steady decline in the knowledge base which parents possess at meetings in which they discussed their child. Far too often, there were so many professionals at the meeting, the parents were intimidated before the meeting even began. The process was very often a dehumanizing one, due to the "bad" news that was communicated in a cold, unfeeling way.

I feel strongly that parents should have support in meetings so that an attitude of "we"—"they" isn't established, but rather that a cooperative relationship is established. Through parent AND professional education, I think this can be accomplished.

MARGUERITE F. GIBBONS.

Name: Maria Gilbert.

Address: 961 NE 73 St., Miami, FL 33138.

Telephone: (305) 758-5322.

The testimony written below represents:

1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

While pre-natal care is extremely important to minimize the risks involved in the birth of a child, public education and acceptance of those already born with defects is crucial. I am an educated (master's degree in clinical psychology), middle class white female, who did everything "correctly" during my pregnancy and still gave birth to a mentally retarded child.

At her current age of 17 years, I cannot begin to tell you the horrors we have experienced in receiving services for her (Dade Co). I am firmly convinced that she would not have achieved as much as she has, if I had not been verbal, aggressive, pushy, educated and unwilling to take no for an answer and give up. I shudder at the thought of the numbers of children who need services and whose parents are not able to do the above to fight for their child. This is not to mention the overwhelming emotional strains that we have endured. However, after 21, I will have nothing to fight for for her because there is nothing available. The one thing I want the most for my child is acceptance. Acceptance from the people around her. Acceptance does not cost the government or the State one penny. Acceptance comes from exposure, example and from the top down. I hope you will help dispel unnecessary fears by "spreading the word" with your family, peers, and constituents.

Thank you for your time today and thank you for reading this testimony and for your concern.

Sincerely,

Maria Gilbert.

Name: Joan A. Halligan.
Address: 2120 Kennen Dr., Valrico, FL 33594.
Telephone: 814-685-1835.
The testimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: No.
3. Research/Other: No.

Our son thanks to modern medicine and thousands and thousands of dollars has lived to be 23 years old. The years of suffering and financial hardship was worse than the defect itself. Please help these children that are now being born to lighten the financial load on the families by giving them some financial aid.

The health care cf today gets worse every day and its adding more burdens to these family.

To know these children is to love them. Special people deserve special help.

Talk with us and you'll understand what we are talking about.

Thank you,

Mrs. Joan A. Halligan.

Name: Judith R. Hansen, R.P.T.
Address: 137 B Blue Heron Drive, Daytona Beach, FL 32019.
Telephone: (904) 761-5126.
The testimony written below represents:
1. Personal experience in my family: No.
2. Work related experience: Yes.
3. Research/Other: No.

I would like to see more provision for:

1. Counseling of parents as they try to deal realistically with their child's disability.
2. parents with transportation problems that interfere with scheduled therapy appointments.
3. care of siblings to free up parents to observe during treatment sessions.
4. increased availability of funds for continuing education or a means of more immediate sharing following a con't. ed. experience.

Judith R. Hansen, R.P.T.

Name: Ms. Margaret Hartig, So. Fla. Society for Autistic Children.
Address: 12478 North Bayshore Drive, North Miami, FL 33181.
Telephone: (305) 893-3712 (Home) 545-0505 (Work).
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other: no.

Although the issues of pre-natal and neo-natal care are of extreme importance and must be addressed, I was a little disappointed that the congressional hearings did not address the issues concerning the thousands of handicapped children that are already here, and who are not receiving the services that they desperately need in order to survive in our world.

As a parent of a 16 year old son with Autism, I find it appalling that there are no services in Dade County which will accept my son upon graduation from school at the age of 21. Autism has always been the forgotten handicap. We must start providing services for these special people. At present they do not have equal access to the funds allocated for developmental services. A survey of all the providers in Dade County several years ago revealed that none of them would accept Autistic persons in their Developmental Training Programs or Residential Programs. We must have additional funding provided for the Autistic population. They have a right to enjoy and take part in programs in their community just like everyone else.

Please remember our children when deciding who will get what funds.

MARGARET HARTIG.

Name: Shirley W. Hartley.
Address: 860 S.W. 18th Street, Boca Raton, FL 33432.
Telephone: (305) 368-8023 (h) 305-391-1504 (w).
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other: no.

As a delegate attending the 1987 Parent-to-Parent of Florida conference, it was a pleasure to learn of the opportunity to provide testimony on the need for funding for additional services for mentally and physically handicapped children.

And as the parent of a 16 year old moderately mentally handicapped daughter, I would like to express my appreciation for the services she is now receiving in Palm Beach County—educational, through the school system; and leisure time activities, through Palm Beach County Parks & Recreation.

My concern is the need for programs or care for my daughter when she is not in school. There is no respite program available in our county; and the after-school program runs for a period of only a few weeks in the spring and in the fall, and then only until 4:00 p.m. What is a working mother to do?

I would hope that there would be a group residential facility available for my daughter in five or six years, but am deeply concerned with the lengthy waiting lists for such facilities and the problems with zoning which exist. Certainly an infusion of funding is needed here, as well as greater pressure put on our elected local officials, who need to be educated about group homes in our communities.

And my deepest concern, as an ARC staff member involved with our infant intervention and developmental preschool training programs, is lengthy waiting lists. It is truly a crime to not be able to provide the necessary services to children simply because of lack of funding, when it has been proved that early intervention can improve developmental growth for the lifetime of the child.

SHIRLEY W. HARTLEY.

Name: Mrs. Sharon Hartzell.
Address: 23213 Olean Blvd., Port Charlotte, FL 33952.
Telephone: (813) 629-2808.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: yes.

This is an account of the problems I have encountered in the "Medicaid System". We have a child, 8 years old, diagnosed as severe spastic cerebral palsy. He is also mentally deficient. At the present there are no doctors in Charlotte county who will accept our son's Medicaid. The closest doctor that we know of is 80 miles round trip away from us. Quite a trip with a child with a high fever . . . or a child who is prone to many illnesses . . . or even a sick adult.

I have spoken to a few of the doctors in our community concerning this problem and it seems unanimous that the thing holding back most doctors from accepting medicaid is not so much how much it pays, its how much paper work is involved in accepting it. It seems a travesty that we are given a form of medical protection for our child but are unable to use it. We are a low- middle income family of four with an annual income of $11,000 and we cannot afford to give up this benefit. At present, we have been taking our son to the hospital emergency room for treatment, as they will accept the medicaid. But how sad that our son must go through the trauma of going to a hospital every time he needs so much as a prescription for the common cold. It would not take much to change this flaw in the system so that medicaid could become the aid it is supposed to be.

MRS. SHARON HARTZELL.

Name: Mrs. Sharon Hartzell.
Address: 23213 Olean Blvd., Port Charlotte, FL 33952.
Telephone: (813) 629-2808.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I write in the hopes that another family will not have to go through what we did in order to receive an electric wheelchair for our son. First, I will give you a short history on our son:

Johnny was born eight years ago with severe spastic cerebral palsy. Although he has no speech and is mentally deficient, he seems to understand most of what goes on around him. He has been tested and found that he does understand cause and effect and is at present working with computers at his school.

In early 1984 we went to CMS to ask for help in acquiring an electric chair. We felt, along with his teachers and therapists, that if Johnny was ever going to experience any form of independence, a specially adapted electric chair would do it. He had no chances of ever walking.

Many times over the next 1½ years we were approved and then turned down by CMS. Money was a factor. Also would it be of benefit to the community for Johnny to have such a chair? No, it would only benefit Johnny. Sorry . . . I then wrote to President Reagan on the matter who put me in touch with a wonderful man, a Mr. Bruce Harter with the Governors Advocacy for the handicapped. With his help and another 1½ years of hard work and letter writing Johnny was funded for the chair through Developmental Services.

The sad part is that three important years in Johnnys life were wasted fighting for a chair he would eventually get anyway. This was a very important time in his development. It got to a point of seeing who would hold out the longest. I was even told at one time that I would not get the chair because I stepped on too many toes. Who lost . . . only Johnny . . . three important years.

Please don't get me wrong we are happy to have the chair, sad for what it took to get it.

MRS. SHARON HARTZELL.

Name: Margaret Haugh.
Address: 327 SE 32 Terrace, Cape Coral, FL 33904.
Telephone: (813) 574-5578.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I would like you to strongly support PL 99-457 and to make sure that there are *funds to implement it.* My daughter, 4½ years old with Down Syndrome, receives instruction daily from a non-profit agency (Impact). This program does not provide adequate physical therapy or speech therapy (because of funding). My health insurance will not cover these expenses. They are not able to keep qualified and experienced teachers because of the inability to pay them competitively. There are no appropriate public school programs available for my child until she reaches age 5. Lee County schools offer limited services to 3-5 year olds and no services for 0-2.

It has been a tremendous burden to me to secure transportation for my child to get to "preschool." I need to work to keep my health insurance. I have had difficulties finding babysitters and/or day care facilities.

Impact developmental education for handicapped children in Lee County has been a tremendous help to my child; infant stimulation, preschool, and speech therapy as often as possible. I am very appreciative of the HRS support given them.

MARGARET S. HAUGH.

Name: Kathleen T. Jenkins, MD., Medical Director.
Address: East Pasco Health Clinic, 1110 Ft. King Road, Dade City, FL 33525.

Telephone: (904) 567-0671.
The testimony written below represents:
1. Personal experience in my family: no.
2.Work related experience: yes.
3. Research/Other: no.

I was assigned to Pasco County to serve my obligation to National Health Service Corp. since 1984. I had to provide prenatal care, delivery and post natal care for many high risk patients. After over 300 deliveries, I can no longer provide this service because of malpractice crisis (general practice). Many of the testimonies heard by patients, nurses and physicians have occurred in our community also. Maternal and infant transfers have been difficult because of lack of funds. This has slowly improved during my tenure because of the CARE LINE.

We have closed our prenatal service since January 1987 because of no OB/Gyn available in our clinic. This is the first time since starting the service in 1982. It has been difficult to retain OB/Gyn because of the overwhelming demand and risk. We are presently trying to recruit two OB/Gyn from NHSC. In the meantime, our infant mortality rate and incidence prematurely will increase.

Suggestions:

One. Increase Medicaid reimbursement to help continued survival of Community Health Clinic.

Two. Continued Medicaid to encourage incentive of local physicians to provide needed maternal and child care.

Three. Need to assure Federal funding to maintain present NHSC assignees and community health centers for years to come.

Four. Easier access for indignent patients for services needed.

Thank you for your continued understanding and support for the care of my patients.

KATHLEEN L. PERKINS, M.D.

Name: Cynthia S. Kirsch.
Address: 7856 NW 7 Court Plantation, FL 33324.
Telephone: (305) 473-8789.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Facilities are needed to assist learning disabled pre-school aged children develop and prepare for entrance in (K-12) public schools. Please attempt to organize these efforts in the Broward County area, since these types of programs are not available now. There are many children who need help, many qualified teachers and too few facilities for them. These kids need special help and they depend on you.

Thank you,

CYNTHIA S. KIRSCH.

Name: Mrs. Arlene Lakin.
Address: 5591 NE 28 Avenue, Ft. Lauderdale, FL 33308.
Telephone: (305) 771-9924.
The testimony written below represents;
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My son, Douglas Lakin, will be 3 years old tomorrow. He was born with a small bowel malformation necessitating 2 major surgeries at birth. Three other surgeries were performed for hernias and for his deafness. Our son is 1 of 33 reported cases of a rare syndrome, Opitz-Kaveggia—he is profoundly mentally retarded and deaf.

Our concern is the need for more residential facilities. In Broward County, Fla., there are over 200 children waiting for residential placement! Presently there is a moratorium on placements in HRS funded facilities due to insufficient State funds. Federally-funded facilities (ICFMR's) have the funding but not enough beds for the growing numbers of profoundly disabled children. Along with the population explosion of normal babies comes also more disabled babies. There are some families who went to keep their children at home because they are higher functioning or because, for personal reasons, the family does not went to place their child out of the home for the most profoundly disabled children, families after choose placement so their kids can have the 24 hr. a day care they need.

The problem is funding. We need more ICFMR's (medicaid monies) for these growing members of disabled children. Very few families can afford private placement. Private placement averages $25,000 per year that is base cost only.

We need unfortunately, to "bite the bullet i.e., raise taxes, weed out wasteful spending, and encourage private insurance companies to come up with coverage for catastrophic illness to cover residential placement.

Our son will be placed shortly at the Sunrise ICFMR facility in Homestead Fla. We were lucky—an understatement!!! Many, many other live in despair waiting for an opening—marriages are dissolving, parents are suffering from depression, and some of these kids eventually fall into the "abused children" category.

Please—push for more residential facility funding—we need more ICFMR's nationwide and, especially in Florida.

Sincerely,

ARLENE LAKIN.

Name: Lou Ann Long.
Address: 4875 6th Ave. SW., Naples, FL 33999.
Telephone: (813) 455-1522.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My three year old son was born premature with severe medical problems and was given the prognosis of 0-10% of survival. My husband had to make the decision whether to continue our fight to save our son's life—he said go for it even if it costs a million dollars. He's our son and we'll be glad to have him anyway we can. Especially since I was an infertility patient taking hormones for 5 years to conceive our little miracle. Our little guy made the lear jet trip to All Childrens in St. Petersburg, FL. We were told that Jeremy was the sickest baby they ever transported. Well, our little guy was bound to amaze the doctors everyday. It was the most dreadful months we have ever endured. When Jeremy was able to come home the doctors were very unsure of Jeremy's capabilities and what to expect—but as the doctors told us many times, a parent's love and devotion can cure much more than science.

Our little miracle is working above normal level in all categories—he does have attention deficit disorder, hyperactive and has possible arthritis in both his knees—but this is very minor compared to brain damage and blindness as we once were told.

Without the help of our fantastic doctors and the step-by-step program which is our early intervention program Jeremy may not be what he is today.

The first year of Jeremy's life was very rough mentally and the financial strain—put upon us was beyond compare.

We hope the legislature continues to strive and help the high risk and handicapped children of the world—so many more can have a fighting chance for a happy life or as happy as they possibly can.

Thank you.

LOU ANN LONG.

Name: H. Sue Lundy.
Address: 10813 Providence Oaks Dr., Riverview, FL 33569.
Telephone (813) 689-7520.
The testimony written below represents:
1. Person experience in my family: yes.
Work related experience: no.
3. Research/Other: no.

My husband and I were older parents, who were both accountants for the Fed. Gov't. (DCAA). We had an excellent income and one beautiful healthy son when our daughter was born. I had received high-risk prenatal care at Tulane in N.O., La. and all tests results showed a healthy baby girl. When she was born she was blind, had a dislocated hip, a club foot, an abnormal spinal structure and a neurogenic bladder. She is 2½ years old and very bright. She has had 19 surgical procedures, numerous tests and hospital stays, a two-month hospital stay while in traction, four months of a body cast, constant medication, and has to be catheterized four times a day. She now has some sight and receives in-home vision services. Julia's problems are very similar to spina bifida children with vision problems in addition. Even though she doesn't have the right label to be served as a developmental delayed child by HRS and therefore, even though we would be willing to pay in full, we are not able to obtain either respite care or child care services.

I was told that respite care could not serve everyone, because "it would open the floodgates to all those with needs."

Julia won't qualify for school programs until she is almost 4 because of an Oct. birthday.

The birth of our daughter has brought us great joy, as well as pain and she is worth it. However, due to her birth our income was reduced by 45% because I had to leave my job as a senior auditor. Our bills further reduced our savings to nearly nothing. We have been contributing members of society, but when we need some assistance, we are not eligible. We have no family support because they live too far away. Our insurance won't pay these types of services.

We need either child care so I can return to work to be able to pay for her needs or respite care to help relieve the tremendous stresses caused by her medical needs, her developmental needs, the needs of her sibling due to emotional problems caused by all of this, financial problems and now the marital problems caused by all of this. My husband and I have had literally no time together as a couple since her birth. We do have a 14 yr. old who will babysit, but we can't stay long and have to return home in the middle of our night out, to catheterize her and give her medicine. We did fly my parents down to stay for awhile, but my father is an 80 yr. old stroke victim who is bedridden. We can no longer afford the cost of two air-line tickets and rental of a hospital bed to get a night out on the town.

Every parent who has a handicapped child needs respite care, whatever their income. There is such a gap for the middle income families. The only respite program I could qualify for cost $18.50 an hour. I can't afford that. Not only should it be affordable, but be quality care.

Thank you for your time.

H. SUE LUNDY.

Name: Linda R. Machado.
Address: 12040 SW 121 Terrace, Miami, FL 33186.
Telephone: (305) 233-4593.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other: yes.

I was pleased to be able to attend the First Statewide Parent to Parent Conference in Tampa from March 19th to March 21st. It was an exhilarating experience to be among 500 parents from our State gathered to identify and articulate the needs of our handicapped children on a local, state and federal level. By far, the most promising part of this three day conference would be the opportunity to bring these needs to the attention of Senator Lawton A. Chiles during the Congressional Hearing on Infant Mortality and Child Health. It was truly a disappointment to all the parents of handicapped children to witness that these needs were never addressed due to the fact that testimony had been pre-selected to underscore the efforts of the Prevention Task Force and there was no public testimony from the floor.

Parents of handicapped children are the most active advocates for the need to provide excellent perinatal health care in order to avoid conditions which lead to a life-time of chronic illness, physical and mental disabilities in children. We live with the tragedy every day of our lives and we will die with the anguish of being survived by permanently defenseless children who will be alone and uncared for in a world intolerant of the less than perfect. However, because of what has happened to us, we recognize that while 50% of all disabling conditions are preventable, it is also critical to address the provision of an adequate quality of life to those children born of the other 50%.

Parents attending the First Statewide Parent to Parent Conference in Tampa have all made the extraordinary commitment to advocate for all handicapped children because there are so very few parents who emotionally and financially survive their birth. The majority of the parents at this conference come from a mid-to-high socio-economic strata. The majority of us are relatively well-educated and prior to the birth of our disabled children are likely to have lived fairly comfortably. It is also likely that all of us received what we felt was appropriate prenatel care by an Obstetrics/Gynecology specialist and our children were in all likelihood born at one of the local hospitals that provides maternity care. What links us all together is that despite taking all the necessary measures to create an environment for the birth of a happy and healthy child, we all give birth to chronically ill and/or disabled children. What bonds us is that despite the physical and mental conditions of our children, we accept them as they are, we love them fiercely and can not understand how despite the drafting of legislation necessary to defend their basic civil and human rights, our children still fall through the cracks.

There is no greater frustration for a parent of a handicapped child than to realize that there is little time for the parenting, nurturing and loving of our children because we are forced to become medical, educational and legal experts in addition to being a parent of a child with special needs. We are required to administer medications which are often toxic to our children, so that it is our hand that slowly kills them as we extend their lives by easing their symptoms. We are required to keep up to date on the latest medical technology and advances in order to assure our children and ourselves that our decisions for treatment are in their best interest and that our children are given every opportunity for a positive outcome. Before our children enter the school system, we must have already formulated an opinion as to an educational placement for our child, what assessments are appropriate, what related services need to be provided and what we need to do to ensure that this is done. There is practically no parent of a handicapped child who cannot quote to you every line of Public Law 94-142, Section 504 of the Rehabilitation Act, Public Law 89-313, Public Law 99-457, etc. In addition to which are the repeated emergency hospitalizations in the middle of the night, no sleep for literally years on end, the loss of jobs when the employer cannot give us anymore time off to be with our children, the unavoidable neglect of our other children, medical debts in the millions of dollars and often the loss of our homes and damage to our credit history when attempting to pay them. There are doctors who have even levied an 18% annual finance charge on the balance due for services rendered to chronically ill/disabled neonates! I do not know of any parents of a non-handicapped child to have such demands placed upon them.

It should not be surprising then that the majority of our families are comprised of women as single-parent heads of household for whom the lack of emotional and financial support from the former spouse is common-place and for whom the humiliation and degradation of begging for medical and social services from federal and state agencies is gladly tolerated in the hope of obtaining some relief. But the relief never comes.

President Reagan and others in the federal government frequently articulate the right to life of the unborn and their disdain for abortion. What our government does to us and our children is nothing short of a "post-partum abortion" by not providing the adequate resources for our children on an unequivocable federal scale without room for state or local "interpretations", ridiculous eligibility criteria and the invasion of every aspect of our personal lives. By doing so, it is our national disgrace that we recognize the right to life of the unborn without recognizing the right to a life with dignity of those born chronically ill and/or disabled.

LINDA R. MACHADO.

Name: Sarah Magers.
Address: 302A Whitehall Ct., Tampa, FL 33604.
Telephone: (813) 933-2350.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My daughter Amy was born with Spina Bifida on April 18th, 1972. She's had a total of 18 surgeries and many other hospitalizations due to infections. She is incontinent and will be all her life and will need adult diapers etc. She also needs special braces to sit and stand or walk. And wheel chairs. I am a single parent (my husband is deceased) and I cannot get insurance for her. She's on constant medication for seizures and infections.

SARAH MAGERS.

Name: Sally J. Masters.
Address: 2918 Lantern Dr., So. Daytona, FL 32019.
Telephone: (904) 767-3895.
The testimony written below represents:
1. Personal experience in my family: yes.

2. Work related experience: yes.
3. Research/Other: yes.

My husband and I have been foster parents for 13 years, caring for many disabled children during this time. We have been able to see many injustices in the system, such as the fact that children whose parents place them in foster care receive many more benefits than those cared for in their own home, forcing low income families, in some instances, to place their children.

Recently we adopted a child with Down Syndrome and are now experiencing first-hand the discrimination that disabled children receive. At this writing we have been unable to secure health insurance for our son who is a healthy little boy, but bears the label of Down Syndrome.

There is a desperate need for adoptive homes for disabled children, but it is not surprising there are not more homes available when barriers like this are placed in their way.

Sally J. Masters.

Name: Diana Mathews.
Address: 4805 S.W. 45th Street, Gainesville, FL 32608.
Telephone: (904) 378-1827.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other (Medical literature): yes.

I hope this written testimony can be considered in the congressional hearing on infant mortality and child health.

I have given testimony in each of the three areas designated. I brought this form home with me because I wished to provide the enclosed example of research of medical literature which I have done at the Shands Medical Center Library.

Diana C. Mathews.

Enclosure attached.

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1. Personal Experience in My Family:

My son has epilepsy, autism, choreoathetosis cerebral palsy, and psychomotor retardation. I had excellent prenatal care. The labor and delivery were normal. The baby weighed 8 pounds, 12 ounces with an APGAR of 10 at birth and a 5-minute APGAR of 10, which is the highest score possible for new born babies. The fall of his second year my son had an illness with a high fever and seizures. We rushed him to the hospital. An EEG and x-ray series were reported to us as being normal.

A month later Jack had another illness with fever and another convulsion. Our pediatrician referred us to the pediatric neurology department at Shands. Jack was given a physical exam, placed on phenobartibal and discharged home.

In December of 1975, he was given a follow up examination. He was reported to be a developmentally normal two-year-old, which was his chronological age, on the Denver Developmental examination. In June of 1976, Jack was diagnosed as having choreoathetosis cerebral palsy. He was reported to have psychomotor retardation possibly due to the cerebral palsy. He was noted to be hyperactive due to the drug administered for seizure control, thus Jack's medication was changed from phenobarbital to mebaral, which is another form of barbiturate.

By August of 1977, the neurologist's letter describes this child as behaving in the manner of an "autistic" child. During this time period, nursery schools were recommended without mentioning the appropriate placement for a child who had no self-care skills. I had sought some placement and outside help, but I received recommendations for institutionalization with advice that our family was too middle class for social help even though CMS, an autistic program. We were definitely too poor for private treatment at the cost of $30,000 per year, which was not insured under the family's health policy. Even if it had been, how could the family decide to use up the $250,000 allowance leaving them without health insurance after a few years of treatment?

Let me state clearly that every child born in the United States is dependent upon medical art for his or her growth and development, for the central nervous system of the young child is extremely vulnerable. As in my son's case, seizures may often be the first sign that a problem exists. There are many other soft neurological signs, and the medical literature reports that in the young child the central nervous system is the first part of the body to be damaged if there are underlying nutritional problems. Most people believe this simply means poor diet, but many children are born with individual biochemical needs, which require exceptional diagnostic ability on the part of a physician as well as careful history taking and respect for the parent as observer. Even though we had medical care for our son, we watched him deteriorate for some "unknown" reason, and during this time period, he apparently had no biochemical evaluation. Jack's form of cerebral palsy is reported in the literature to result most frequently from liver damage in the child under five. An extensive amount of research is indicating that autism has biochemical foundations. This information is based on the research component of the third part of my testimony, which was why I brought the form home, for we must come to terms with the new developments in biochemistry if we expect to have any effective children's health programs in our country.

While the focus of the Congressional Hearing on March 21, 1987, was on maternal and health care, we must recognize that children need excellent medical services focused on the latest medical arts during the first five years of life. According to the medical literature, at birth a baby has about 25% of its brain, thus the other 75% of a child's brain growth happens during the first five years of life. Appropriate medical care is absolutely essential during this period of life. If the brain does not develop properly during this time, the family and society is left with the terrible cost in economic and social tragedy.

The issue is often raised about the cost-benefit value of any federal program on social policy. Some of the following information might appear hypothetical, but it can be justified as reasonable for many families and children, thus it could conceivably be multiplied for every special child and family in our country. What, indeed, does this cost?

Jack.—Various figures are provided for the total cost of maintaining the life of a dependent person. The opening speaker on March 21, 1987, reported that the current figures were a lifetime average of $1,000,000 per institutionalized person. This dollar value can be decreased for every year the family retains the child at home, thus our family has saved government institutions nearly $250,000. If the family is able to care for Jack at home half of his life, another $250,000 might be saved. Jack is profoundly handicapped, so eventually he will live in an institution in all probability, but his family will have been able to save society from a $500,000 bill for his care. Balance this information against the possibility that if his biochemical problem had been diagnosed and treated, he probably would not be profoundly handicapped.

What has the country lost in terms of Jack's potential? Clearly, his productive life is now a dependent life. This in no way means it is less than human. Based on two hundred years of family history, there is some justification for believing Jack would have been an extremely productive citizen. Maternally, he is descended from several ancestors who fought in the American Revolution. In this 200th year since the framing of the Constitution, let it be a matter of public record that Jack is descended from one of the signers of this document: Jared Ingersoll. Paternally, he is descended from Florida pioneers. One of his great grandfathers was the first chaplain to speak in what was then the new Florida State Legistative building. This boy who cannot talk is also descended from a Baptist preacher that was actively preaching for over 62 years. While there is no way to know whether or not Jack would have been an excellent citizen, it is probable that the potential was definitely there so what is the dollar value of a "good citizen?"

Mother.—She graduated with highest honors receiving a B.A. in 1973 and stayed home while working on a Master of Education degree receiving it in 1975. In the fall of 1975, she was offered five teaching positions, but Jack began to have his seizure problems. Naturally, she was unable to work. Assumming she had started at approximately $14,000 and continued to work, she would have received salary increases. Perhaps she would have averaged a career earnings of about $20,000 per year, thus as of 1987, she has not earned an expected $250,000. When Jack first went to a special public school, he had to be on Hospital/Homebound due to illnesses. Once he started attending school regularly, he still was ill often enough to prevent regular employment because a teacher must not have a high rate of absences from work. For this reason, the prospects for future employment are no better, and there will be a loss of an additional twenty years of career with a top income level of possibly $30,000 per year. So lifetime earnings of an additional $500,000 will be lost with no old age benefits. Certainly, prevention is the ultimate answer, but how can the family be helped if they do what is "morally right" in caring for their child once the developmental disability has happened?

Father.—Jack's father received a Bachelor of Arts degree with a major in Economics. He began working in a state job, which might pay less than private enterprise, but it offers more benefits and stability, for which the family is thankful. He feels his own situation has remained fairly static because he has been unable to consider applying for other positions due to his focusing too much time and energy on the special needs child. Family income has remained at a level which has qualified it for reduced lunch. It is only hypothetical to suppose that the father could have advanced in income had he been able to focus on his career, but it seems probable. Grandparents have compassionately helped the family improve living conditions; however, the husband's parents have informed him that he will not inherit their property because they know he does not have the income to pay inheritance and property taxes. They are only being realistic. Thus my husband has not received possible job promotions, and he will not receive an inheritance. He worries constantly about facing bankruptcy, and according to the first speaker on March 21, 1987, this is a realistic factor for the family of a special needs child. How should these economic considerations be computed? This is a too typical condition in a special needs family, and quite often fathers solve the problem by leaving, thus throwing the family onto public care lists; yet many fathers do care for their special families and feel some assistance directly to the family would bring unmeasured benefits as the family unit is strengthened.

Siblings.—As Jack did not have a seizure condition until the older children were 11 and 8, they had experienced a relatively normal family life; however, the family had lived in a state of economically low income while father and mother each worked to put the other through college. Of course, the expectation was that the family income would increase upon mother entering the work force, thus the older siblings were advised they would receive benefits for their patience with the relative poverty of college students' lives. This is the American dream. Obviously, this never happened. For every family of special needs children, many dreams die due to unexpected relative poverty if they are among the working poor or unable to obtain the two income level of many American families. The older siblings report that the lack of direct parental involvement in their activities from sports to clubs deprived them of many of the experiences their peers were having at the time. There were no trips or other important extra family activities because there was no extra money or time. Possibly sibs experience more social frustration because there are two choices regarding friends. The first option is to go out of the home, which is challenging in today's youth culture. The second is to bring home only friends that accept the handicapped sib. Can this be measured in dollars?

The youngest sibling has not known a home without her special needs brother. Having a baby to care for at home, I thought it would be a blessing to have Jack in school the fall of 1979. Instead, the family learned that among handicapped people there are what is known as "institutional" diseases. State clients go to Jack's school, and soon all sorts of illnesses were being experienced at home. Some of the illnesses were repeated streps, and the baby was evaluated at the Shands Kidney Clinic because she appeared to be developing a kidney problem.

Fortunately, she was found to be all right, but she experienced a great deal of unusual illness and a traumatic IVP at the clinic when she was two. Thus the family of a special needs child may have some additional medical expenses due to illness that are outside of the normal range of expected childhood illnesses. Clearly, the family of a special needs child has many unexpected additional needs for each family member. Who can calculate the cost to parents and siblings of all of the hidden factors involved in living with a special needs person? For this reason the prevention of one child's developmental disability can save untold amounts to the disabled child, family, and community. Furthermore, the family of a special needs child needs community support if people really believe the best place for this child is with the family; especially if anyone really thinks children with exceptional needs medically and educationally can benefit society by being at home rather than in an institution. These policy matters must have thoughtful consideration of the type that our political leaders have already so carefully invested in this issue.

2. Work Related Experience:

When my youngest daughter went to kindergarten, I was offered a morning position as a teacher's aide. I found I was able to fit this into my schedule as it was a three hour a day job, thus I worked for a school year with kindergarten children.

From this experience, I concluded we have had too many at risk children in the early years because many of them arrive at school with medical, social, and emotional problems. The new legislation has addressed this issue by providing for early intervention, but I think this intervention must be directed toward recent findings in research. Young children do not perform well if they are deprived of early nurture; yet, we are, as a nation, encouraging young mothers to work. Designing the type of day care program necessary to replace quality mothering would cost more than providing training and support for decent family life. Russia and Israel tried with some of the best programs in human history to have day care programs. Check the records there and learn what has been found out about early human development. While the United States has provided monetary care for dependent children, it is no secret that this was unfortunately designed in a way that weakened the family. For example, one of the women testified in the Congressional Hearing on March 21, 1987, that she couldn't receive help as a married woman. Thus several factors must be considered as new legislation, which ultimately is aimed at the family, is enacted. As a matter of fact, I have included under research the information by a Harvard medical doctor that the ideal situation for maximum brain development is for the human child to be nursed at breast until the age of 3. This, as he acknowledged, is unlikely to happen. Nevertheless, there is extensive medical evidence to back up this position of breast milk being the best possible preventative of developmental disabilities; yet, few programs provide any encouragement to a mother who wishes to breast feed her infant for even the highly recommended six months. Needless to say, the breastfeeding mother must have proper health care to provide quality milk to the infant, thus a continuum of care is needed for mother and child prior to conception until a few years after birth if the goal is to minimize developmental disabilities.

I helped with health screening and developmental screening, and I know our children are showing some serious problems. I believe anyone could participate in these experiences at any comparable elementary school in the United States and draw the same conclusions. In fact, a surgeon general's report concludes that 1 in every 25 children is hyperactive, which is a soft sign of CNS problems, and this places a hyperactive child in every classroom. The picture is not all gloom and doom, though, for there are some bright and talented young children in America. Human beings are remarkably resilient. The question is how many children can we afford to place at risk from birth through the first five years of life because we are unwilling to accept some biological and psychological realities about human growth and development? While many people may question whether or not we have reliable knowledge in these areas, there are some directives.

My second year of work experience involved a position as a Chapter I Aide. I tutored 5th grade students below the 50th percentile on the Metropolitan Achievement Test. Later in the year, I worked with 2nd and 3rd grade Chapter I students. These are the students who are really lost in that gray area of developmental delays, which are hardly noticeable in terms of physical problems, but they reveal themselves in educational problems. These are students who cannot perform academically on grade level for various reasons. Some are learning disabled, some have medical problems, and some have environmental problems. From my research in the medical literature, I am relatively certain that some of these children had medical problems that were undiagnosed thus untreated. For example, one boy would come in periodically looking very yellow. Children would come to school and develop headaches and stomachaches. One boy's file actually had the information that nutritional intervention had been recommended by a dietician. Of course, there was obesity. There were even children that looked like they had come from the starvation belts in Africa. I believe anyone could find the same children in a comparable public school in the United States.

What will be the cost to our country for these children that may live independent lives but grow to be adults with minimal skills because we have not understood we need an improvement in medical and environmental prevention of developmental delays from conception to the age of five years.

3. Research/Other (Medical Literature):

While I heard testimony at the Congressional Hearing on Infant Mortality and Child Health about the importance of prenatal and birth care for children, I know it is a matter of record that only about half of the development delays diagnosed in children originate in this area. Infant mortality is tragic, but developmental disability is destructive to the child, the family, and society. I have shared my son's history because it is typical of many case histories in the literature and from personal testimonies of parents through contacts I have with special groups.

Furthermore, I wish to contend that even among so called "educated" people, including doctors, most people do not know what proper nutrition for preschool children may be; yet, in young children poor nutrition will damage the nervous system before any clinical signs begin to appear. Let me be specific. Some people believe the American Heart Association Diet is appropriate for children under 5. This diet could prevent maximum development of children's central nervous system. For some it will be in subtle ways, which may never be recognized: they won't be as corrdinated as they might have been on the proper diet. A child's diet must be 50% fat, and it must be the right type of fat. We are conducting a great experiment in

America with food. While the enclosed photocopy (I) from "The Brain Food Diet for Children" makes the point about critical developmental periods, I have not included other important information, which supports what I am sharing in this paragraph. I feel it would be worthwhile to advise interested persons to examine the book, and I have included a photocopy of the information regarding the book and the author's credentials for this reason. This book provides the best description of brain growth from conception to the fifth birthday that I have found in any materials for the layperson.

Perhaps I am overstating the case because I think that medical science should not be funded at the expense of medical art. Proper diagnosis could prevent some developmental disabilities with correct treatment, and additionally, developmental disabilities can be improved with correct intervention in the early years through biochemical analysis. The next photocopy (II) provides the information that "biochemical data as well as the other four methods of evaluating nutritional status are needed for the DD child." There is no need for the federal government to provide medical care for the public without a strong effort being made to provide this type of medical services to dependent children of the poor, working poor, and middle class. Possibly, the wealthy do not even recognize the need for this type of evaluation, but if they do, they can afford to have these type of evaluations made. The point must be made, though, that parents and professionals have to be aware of the necessity of this type of evaluation when a child begins to show some "psychomotor retardation in the preschool years." The information in resource number III provides this information far better than I could ever do, and I submit that many children have this profile.

Indeed, the enclosed copy of a Shands diet book provides some type of an idea about how extensive this field has become over the past few years. At a recent March of Dimes presentation, I heard the information that a child received B-complex injections prior to birth, which prevented birth defects. Naturally, no parent could treat any suspected disorder without professional help, but it really appears that if these types of disorders are diagnosed and treated, the special interventions will ultimately cost the family and society much less than the aftermath of untreated problems. I didn't know that my son had this type of problem, but his case history sounds as if it is possible, which is the reason I have shared it. It is typical of many case histories as I have already stated. In addition, it is worth mentioning that on an optimal diet, these metabolic problems may not be manifested in the child, but on a marginal diet it may happen. As we are aware, many reputable professionals have reported that even middle class Americans eat a marginal diet low in zinc, magnesium, iron, calcium, vitamin C and the B-Complex vitamins. Furthermore, no one can depend upon supplements because the field of nutrition does not represent comprehensive knowledge of human nutrition, thus appropriate dietary sources are the proper requirement for the well nourished child. Indeed, as the next photocopy (V) indicates, "lessons from the inborn errors in metabolism" provide directions for all of us.

The August 8, 1985, issue of the Gainesville Sun contains an article reporting research done during a Harvard study providing equal access to hospital care, which made no difference in mortality rates between white and black infants. While social class, thus poverty, was reported to be a possible fact, it was found that the figures held for middle class families. Some people might use this research to indicate that providing early medical care does not really make a difference. I think that this research demonstrates the point of my personal testimony regarding the necessity to combine medical science and arts. The "Guide to Normal Nutrition and Diet Modification" written by the staff of the Department of Food and Nutrition Services of Shands Hospital, Inc., at the University of Florida in 1983 provides information on a condition known as lactose intolerance. This condition is well reported in the medical literature; yet, milk is probably recommended to black pregnant women. In addition, I would like to add that those children who developed headaches and stomach aches at the school where I worked were black children who had eaten breakfast. The lunchroom director advised me upon occasion that black children don't like to drink milk, which is the normal response to lactose intolerance due to headaches and stomach aches, and she encouraged them to drink it because it was good for them. I was speechless. Who am I to address this issue being aware of how important this factor is considered to be in the American diet. Nevertheless if black children improve by adolescence, it is tempting to think that they are not made to drink their milk. This might be considered an example of an inborn error of metabolism effecting a large number of people in our population known to have marginal nutrition. The Shands report advises that lactose intolerance provides no problems unless there is marginal nutrition. For my part, I do not know what this means in terms of black children and development, but I have been concerned that appropriate persons address this issue.

In summary, I hope the enclosed research provides additional information regarding our urgent need for appropriate medical care to prevent developmental disabilities. Once the child is unfortunate enough to have a developmental disability, medical care and educational intervention can decrease the severity of the disability, and it might possibly still provide a citizen capable of living an independent and productive life, thus contributing to society rather than adding to the number of totally dependent people so expensively maintained in our country's institutions. Finally, if the family is to be encouraged to care for these children once they are developmentally disabled, they need some recognition for their efforts economically and socially. At least the removable of the fear of bankruptcy due to decreased earnings and increased medical and physical needs as well as the prospects of a destitute old age would help American families with special needs children maintain their dignity as citizens of the United States.

Name: Natalie McClain.
Address: 3317 W. Wyoming Ave., Tampa, FL 33611.
Telephone: (813) 831-2204.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

My son Joseph was born with Spina Bifida on December 17, 1986. We've spent (approx) $50,000 to date, and I'm sure we will spend a lot more this coming year. We're lucky! We do have insurance, but it doesn't cover all of the bills. Joseph has been in the hospital twice since he was born and he's only four months old. His defect has been repaired and he's had his shunt surgery. He will need special shoes to correct his club feet. Please we all need your help.

NATALIE NAHON MCCLAIN.

Name: Kevin D. Miller and Betty Nola Miller.
Address: 2123 Patrick St., Kissimmee, FL 32741.
Telephone: (305) 933-1482.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

We are the parents of a Downs Syndrome Boy (Jonathan). I work on an average of 55 + hours per week and can still not keep up with our finances. We are paying on a Home Mortgage of $50,000, have a seven year old car and living in Osceola County (which has nothing for handicapped children). Everything (that we can find is in Orange County) is a long distance phone call which creates massive phone bills. My wife has to drive 75 miles (round trip) 4 days a week for Jonathan's therapies.

Our problem has been qualifying for SSI money. But they say I make too much money. A 4-pak of nutrient equipped Sustical Pudding costs $6 + dollars of which she feeds him 2 cans a day (per Doc's orders).

I'm told by other parents we will eventually be approved for SSI *but* why must they fight giving it to a handicapped person when he deserves it.

We are also having problems with insurance fighting to pay for therapies and medical bills.

I work for Walt Disney World. Their group insurance company has now listed what hospitals and which doctors you can or cannot use.

We live next to two *very good* hospitals in Kiss.. When my son developed pneumonia we put him in one of these hospitals and insurance OK'd it. However three days later insurance called and said their records indicate that it only takes four days to get well from pneumonia. So the hospital released him. Three days later he was put back in for pneumonia again.

Next insurance stated it was a hospital not on their approved list so they wouldn't pay the first $500 of the bill and then they would only pay their percentages of the remainder.

As to not lose any Disney clients at this hospital they decided to waive the first $500 of the bill. Insurance found this out and then would not pay the first $1000 of the bill. (Jonathan in 2 times 3 days apart creating two bills). This left an immediate bill of $2000 + dollars.

Can you help us and all the people like us having the same problem with financing and qualifying for such funds available.

KEVIN D. MILLER.
BETTY NOLA MILLER.

Name: Helen Nagy.
Address: 10115 Dartmouth Ave., Tampa, FL 33612.
Telephone: (813) 932-4112.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Sir, I have a grandson with spina Bifida and I know how much it cost to have all the operations, which he has to have. Since he is permanently disabled (in a wheelchair) the medical problems are such that he will always be in need of care.

Thank you for your support.

HELEN A NAGY.

Name: Marsha E. Palitz.
Address: 22 Woodlake Dr., Port Orange, FL 32019.
Telephone: (904) 761-1564 (Home) (904) 255-4568 (Work).
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: yes.
3. Research/Other: no.

I am a speech-language pathologist who has been employed in an Early Intervention Program for 5 years. Our program works closely with other agencies, especially the Dept. of Health and Rehabilitative Services and the school system, in order to integrate services as much as possible. As I have worked with disabled pre-schoolers (birth to 4) and their families, I have seen problems or deficits in the following areas:

1. Counselling services.—The presence of a disabled child takes a tremendous toll on a family and most of the families cannot afford private counselling; furthermore, such services need to be on site with other services such as therapy in order to provide easy access.

2. Respite care.—There is a severe lack of trained or experienced people to provide babysitting or day care (or more long term care on an intermittent basis) to give families some relief from the constant care and attention often required by a disabled child.

3. Transportation.—Low income families and families in outlying areas often cannot keep appointments for treatment because of unavailable transportation.

4. Homebound services.—Lack of transportation or illness often prevents children from receiving needed services.

5. Insurance coverage.—Companies often refuse to pay for pediatric occupational therapy or speech-language therapy even when these services address problems which are directly related to the underlying physical disability and have significant effects on the child's long-term functioning and independence.

6. Equipment.—Children often go without needed equipment for a long time because of inadequate funds.

7. School treatment programs.—In general, facilities are poor and the caseloads are far too large for therapists to provide effective services.

8. Continuing education.—More funds need to be made available (through grants, spends, etc.) for a variety of continuing education programs (from 1 day courses to 8 or 10 week courses) aimed at professionals and support staff who are already working in the fields (i.e., services for the disabled children). Training and upgrading of skills is critical to quality care and professional motivation in working with this difficult population, a population with very special needs.

MARSHA E. PALITZ.

Name: E. Robert Petro.
Address: 3202 Colwell St., #606, Tampa, FL 33614.
Telephone: 933-5278.

The testimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: No.
3. Research/Other: No.

DEAR SENATOR CHILES: My daughter, Sarah, was born with Spina Bifida—nerve damage to the spinal cord at birth. Her predicament would be similar to someone who was involved in an auto accident and broke their back.

Sarah has had numerous orthopedic operations to try and correct the muscle imbalance in her legs. She is now fifteen years old and walks in long leg braces.

The point I want to make is that her life gets harder as the years go by. As her body weight increases, it becomes more difficult to walk. This, plus the secondary effects of hydrocephalus and loss of bladder control make Sarah's life difficult.

I am asking for your support in any upcoming legislation regarding Spina Bifida.

E. ROBERT PETRO.

Name: Bonnie C. Poller.
Address: 136 Martinique Lane, Ramrod Key, FL 33042.
Telephone. 872-3616.
The tesimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: No.
3. Research/Other: No.

My profoundly mentally handicapped 9 year old son came home from school one day with a hand print on his bottom from being spanked at school. Of course I called his teacher and principal and we worked it out. At present a law is being presented to repeal the present corporal punishment law (numbers unknown to me). I strongly encourage you to vote in favor of repealing this law to prevent future physical abuses which occur in all the schools. I was also a teacher's assistant, school year 1985-86 and personally witnessed many physical and verbal abuses committed by both teachers and staff. One teacher was actually spanking kindergardners in the classroom. This must stop. People are not for hitting. Children are people and the most vulnerable to abuses. The attitude of adults toward children is in question. The law that allows teachers etc. to hit children encourages a negative attitude. The law must reflect the attitude.

The law is being presented in the House of Representatives and will soon be presented to the Senate.

Thank you.

BONNIE POLLER.

Name: Edmud. Preston.
Address: P.O. Box 855, Seffner, FL 33584.
Telephone: (813) 685-1423.
The testimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: Yes.
3. Research/Other: Yes.

We are writing today to explain the tremendous amount of energy, time and money with a spina bifida child. My brother-in-law who is sixteen, Skipper "Mac" Adams is almost totally paralyzed and totally invalid.

He requires 24 hours care. He is incontinent, requiring adult size pampers. Because of his tremendous medical costs both his parents work long hours requiring baby sitting care by a trained adult. They lose 3 to 4 days a week to his illness. An example of his medical costs are $1,800 per wheelchair, $12,000 for double pneumonia in October 1986, and the list is endless.

Please help.

Thank you for your time.

MR. AND MRS. EDMUD PRESTON.

Name: James Ragin, Jr. and Debra Ann Ragin.
Address: 1261 N.E. 152nd Street, North Miami Beach, FL 33162.
Telephone: (305) 944-0412.
The testimony written below represents:
1. Personal experience in my family: yes.

2. Work related experience: no.
3. Research/Other: no.

In trying to get help through HRS to help pay for our son, Jason E. Ragin School fee, which cost us $475/mo. at the University of Miami Debbie Institute, he only attend 3 hrs a day (5 days a week). Our son was just in November, 1986 diagnostic, as having Cerebral Palsy. We have been on HRS waiting list since he started at the Debbie school in July, 1986. We were told that they have a waiting list. Last month on Dr. Martin Luther King Holdiay they set up an appointment for 8:30 a.m., we missed the appointment because of thinking of the Holdiay. I thought about it at about the time we were supposed to be there. I called HRS office and tried to talk with Ms. Diaz's Secretary. I was told she was not in that day. I ask to speak with Ms. Diaz, she was in a meeting. So the following day I call back to try and set up another appointment and was told that they would be setting up appointment within the next two weeks. Please, as a parent and I think that I am speaking for all parents, help us to get the necessary help as soon as possible, especially for our special childrens in America.

Statewide Referral System is highly recommended.

Dear Senators, Legislators, Congressmen,

Please hear our plea as a parent with a handicap or disable child. To me they are our special children, who need all the available help that is possible for them to have through all types of fundings. I mean funding not only for the family who is eligible for funding, but also for family or denied special funding. Every single child with a handicap or disability should be eligible fo: any type of funding from all agencies. We as parents need your help in helping our children to get the special care that they need.

My child Jason E. Ragin was a full 9 mo. He weight was 8lb, 9oz, we brought him home. When he was 1½ mo. his eyes began to cross. We had to take him to an eye specialist where he was diagnostic as been far-sighted and had to wear bi-focus. Just recently he got a new pair of glasses which is just a little better. When he was 3 mo. we notice he wasn't doing things normal the way our other 2 children did at that time. That's when we made an appointment with the University of Miami; mailman center (last year April, 1986). He was tested and evaluated their. He saw a neurology that suggested he attend the Debbie institute for therapy. The neurologist diagnosed his as being at High Risk in order for him to attend the school.

In November, 1986, Jason was diagnosed as having Cerebral Palsy. I think that is to long for any parent to wait and then to find out the problem your child have, or hoping that they are normal all of that time before.

So please think of our special children and help us as parent to get the special care and fundings our children need. Whether they are poor or in the upper class level. I beg you as a perent please help us to get all available fundings, for our special children.

Thank you.

Debra Ann Ragin.

Name: Richard R. and Deborah L. Roddy.
Address: 298 So. Orchard St., Ormond Beach, FL 32074.
Telephone: (904) 677-1453.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: yes.

My son is now 22½ months and has gone thru 110 days of hospitalization and 93 days of sickness at home. My doctors all say they have never seen a child with as many problems as my son. Food and Drug Administration told me between my pregnancy and my sons life that we are the most complicated case in the United States and have the most problems.

My son's problems are: 1. Tetrology of Fallot (heart); 2. Microcephalic; 3. Cerebral Palsy; 4. Undescended Testicles—hernia; 5. Abnormalities (not noticable); 6. Cortical Blindness; 7. Seizures; 8. Obstructive and Central Apnea.

Surgerys: 1. Heart Catherization—2 days old; 2. Right Blalock-Tausig Shunt—2 mths. old; 3. Left Blalock-Tausig Shunt w/Gortex—1 yr. old; 4. Abdominal Surgery (testicles)—w/large hernias; 5. Emergency Tonsils and Adnoids; 6. Awaiting Open Heart Surgery (repair of 4 things).

My son is very handicapped, as you can see—I believe I know the reasons why (but that's another story in which I need help). The most important issue that needs help for the parents and the children is public awareness plus the knowledge of where to get help—Doctors—organizations do not tell you of where you can get help—I never knew there were organizations or different help unless you hear it from parents. More playground w/handicapped activities and swings—more help for the person that has insurance but goes thru money on traveling and eating because their children are in hospitals every 2 wks. for 5 mths.

RICHARD R. RODDY.

Name: Debbie Shea.
516 Maplewood Ave., Port Richey, FL 33568.
Telephone: (813) 862-4675.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I have a Spina Bifida child named Meighas. She is eight years old. Expenses for a S.B. child are great—example—diapers $56/case. We use 1½ cs./mo. × 12 mos. = $1008/yr.; 1 wheelchair at $1800.00 × 3 since birth; 1 brace $2400 × 1 yr.; medicine $20/mo. × 12 = $300/yr.; 1 hospital visit 3 days, $1300—same year $6976.00; surgeon $4000; pediatrician $50/mo. × 12 = $600.00 per year. These are some of the expenses × 8 yrs. have led to enormous bills, not counting legal fees for proper education—psychiatrist—special shoes, normal childhood illness. Please help us.

DEBBIE SHEA.

Name: Elizabeth Stanley, Registered Nurse.
Address: Rt. 5 Box 185, Defuniak Springs, FL 32433.
Telephone: (904) 892-2803.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I anxiously awaited for nine months to see and hold and touch this tiny new person I had been carrying. Suddenly, the words the doctor was saying were not what I had expected to hear. "I am requesting your permission to take a special blood sample to confirm the diagnosis of Down Syndrome." Mental Retardation, developmental delays, cardiac complications, and many other physical complications maybe things we will have to deal with in our child's future. Nine months of good pre-natal care had not prepared me for this moment. I found myself grieving for the child I had expected, and lost, but confronted with a special needs child to care for daily. I had to learn to cope with my feelings of guilt, anger, denial, depression, etc. and not wallow in self pity. This was not hard, when my son would look up at me and smile. I began to think that he would just have a different timetable for accomplishing his milestones, "walking to the beat of a different drummer."

Parents find themselves advocating for their children; because of the misconceptions held by educators, health care professionals as well as the general public. Society handicaps our children, by segregating our children from the world, they also live in. More handicapped (physically & mentally) children are remaining in their own homes, and loved by their families.

The best you legislators can do for us is to encourage home placements where it's possible, and assist families with financial means for physical therapy, speech, etc. to accomplish this. I love my son Patrick, as you love your child.

ELIZABETH STANLEY, R.N.

Name: Margaret Stephen.
Address: 1916 Ivy Lane, Holiday, FL 33590.
Telephone: (813) 938-6111.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Dear Senator Chiles, since our daughter, Summer Stephen was born, may 28th, 1985, we have had many expenses due to her disability, Spina Bifida. The bill at All Childrens Hospital was $50,000. And since then, we make frequent trips to the Shriners hospital and pediatrician. The diaper bills costs us a lot and HRS won't help us. She has bowel & bladder troubles and frequent infections. Please support our Spina Bifida Group.

Thank you so much.

MARGARET STEPHEN.

Name: Sarah Stevens.
Address: 155 Bayview Ave., FMB, FL 33931.
Telephone: (813) 463-1090.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I had a premature baby 13 months ago and after Paul had a 2 week hospital stay, Paul was sent home, with no kind of follow-up care, to ease the transition home. My feelings were, because Gary and I had no financial problems and we are both highly educated, that we therefore needed no real emotional support and/or reassurance once our child was home. When Paul was approximately 5 months old, I was frantic to find help for Paul and us, because I knew Paul had definite developmental delay. He is now in an early childhood stimulation program, which is very helpful, but I feel had there been follow-up directly from the hospital, we all could have had a less traumatic 1st year as a family.

SARAH STEVENS.

Name: Stephanie Walsh.
Address: 1112 Overbrook Drive, Ormond Beach, FL 32074.
Telephone: 904-677-1172.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Our biggest problem has been our insurance company. Because we knowingly adopted a child with brain injuries at birth, they refused to cover her. Under pressure, they said they would cover her after the adoption was final—but not cover any pre-existing conditions. Only after threat of cancellation by my husband's office and other law offices in our area (who had come to our aid) did they finally accept our daughter's policy. They said if she had been our natural daughter there would have been no problem.

Our daughter was referred to the Early Invervention Program at the Volusia Easter Seal Center immediately after we received her. The people there were wonderful and very supportive. Unfortunately the time between referral and actual help was about three months. I feel that one of the most important things to be done, especially for premature and high risk babies, is to set up programs in the hospital so that parents will know how to handle their babies; how to hold them to minimize the posturing of cerebral palsied babies, how to turn them and exercise them, how to deal with seizures, before the baby leaves the intensive care nursery and before the intensive therapy of the EIP program begins.

HRS Florida has been a real hassle for us too. We had to beg for aid for our daughter and present her to them as a complete loss before they would accept her so that she would be eligible for Easter Seals. I feel that if the babie's doctor recommends EIP then the state should accept the doctor's findings instead of making the family suffer and beg through all the hearings and home studies of HRS.

Thanks for listening Senator Chiles!

STEPHANIE S. WALSH.

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146 18TH STREET, N.W.,
Ruskin, FL, March 20, 1987.

Senator LAWTON CHILES,
Washington, DC.

DEAR SENATOR: The Certified Nurse-Midwifery service at Ruskin Health Center, engaged in fullscope practice—prenatal, intrapartal, and postpartal care—established and continued an excellent program demonstrated by its outcomes in 1983, 1984, and 1985. These outcomes have been consistently measured by neonatal birth weights and patients compliance. Low birth weight—infants weighting less than

2500 Grams—are at a much greater risk for problems. Patient compliance demonstrated by kept appointments indicates the willingness of the patient to participate in all other aspects of care as well as willingness to exhibit changed behavior to asure a healthy pregnancy.

At the beginning of 1986 we had six Certified Nurse-Midwives full time and one part-time who covered 88 hours per week at our two clinics and 168 hours per week at the hospital. Our low birth weight at that time and the years preceding was 4.0%, compared to 7.5% for the State of Florida and 8.2% for Hillsborough County. We had 99% postpartal return for mothers and babies delivered by the nurse-midwives, compared with 30 to 40% in the county health department programs.

Since our services were curtailed March 1, 1986—no intrapartal component—our low birth weight rate has risen to 7.0% and our postpartal return is less than 60% in spite of an aggressive outreach program. Our protocols have not changed, the nurse-midwives are still practicing midwifery. Why the difference? The patient knows the nurse-midwife will not participate in what she perceives as the most important aspect of her pregnancy, the birth. This results in poor compliance for changed behavior. Also, compliance is a barameter of patient satisfaction with care.

Are not cutbacks in service in direct opposition to the frame of mind of our congress that has just passed legislation that addresses the need of bringing flexibility to the Medicaid programs, (SOBRA) to make services immediately available to poor women who seek prenatal care.

We hope to continue our service within the framework of the Ruskin Health Center, and will be examining ways to again make this a full service practice to participate at the birth of our women. We thank you for your continued interest and support.

Yours truly,

BETTE WATERS,
Certified Nurse-Midwife.

Name: Mrs. Kathleen Watts.
Address: 415 Fourth Pl., Merritt Island, FL 32953.
Telephone: (305) 459-1788.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I have been told my story is a common one. My daughter Sara is now 5½ years old and is PMH with epilepsy. This was not diag. until she was 2 yrs. old and only then because she started having mild seizures. Her previous delay was thought to be due to severe ear infections. This was all in Massachusetts. The state then started her in classes & offered respite (20 hrs per month with nurses to care for her). When we moved to Fla. in Aug. of '85 I was surprised that no one knew what respite was. But she was finally put in school. We then moved to Brevard County and she again was finally put in school and no respite. Things were very tense in the household. In Aug. of '86 Sara needed some special testing and found out rather rudely that our family insurance will not cover her at all. I then went to SSI, Medicaid and Medically Needy and was told they couldn't help because I was married and my husband made too much money or gave me a $1,500 deductable per month. FDLRS helped all they could but their funds are limited so it fell on us again. No one will help unless you are single or divorced with no money. It would be less expensive to help the families before they break up due to financial and emotional pressure. All parents and families need help now, not in 3, 5 or 10 years. If Sara was in a community home she would be getting all sorts of services but since she's at home we are again in that ever widening 'crack'. It will continue to widen until someone cares enough or gets pushed enough to do something.

KATHLEEN WATTS.

Name: Lorraine and Gary Whitehorn.
Address: 2641 Sunset Drive, New Smyrna Beach, FL 32069.
Telephone: (904) 428-6101
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

Gary and I were married in March 1984. In June 1984 Gary had a minor heart attack. In October 84 he had another one. November of 84 Gary had tripple Bypass Surgery and was hospitalized 2 weeks returning to work the end of January 85. I worked and supported us then. Insurance paid 90% of all the bills. In September 85 we had a premature daughter 8 weeks early and weighing 4 lbs. She had apneas braderadia and was transported to Halifax noenatal unit and was there 30 days, then transported to Shands Hospital in Gainsville where she spent 20 days going the extensive tests and Surgery. She was diagnosed as having "reflux" and has what they call a nissenfuneplication (nissen wrap) where they wrap the stomach around the esophagus. She was spitting up most every meal and this operation stopped that. She came home around the 23rd of November with a gastronomy tube (in her stomach) and a heart monitor ($300.00 mth) she had the gastronomy tube until December 1985 and was on the heart monitor until January 23, 1987.

Hospital Bill: November 1984: 35,000, November 1985: 50,000, January 1987: 40,000, March 1987: 5,000.

I would like to work in the Child development field and have a Degree in Office Education and Bookkeeping with background in computer. I want to work if possible. During 1985-86 Gary, every 6 months had to go to the doctor to have a stress test that cost $150.00. In 1986 every 2 weeks Jessica had to go to the doctors and get weighed. Every three months Jessica saw the doctors at Childrens Medical Services to help pay for the heart monitor, 80%. Every 4 months Shands doctors saw her at Childrens Medical Services for her gastro intestinal problems and follow up surgery. She had x-rays and blood tests every time. Insurance covered 80% of all medical bills but we still had to come up with the 20%. Since Jessica was born I have been unable to work as she takes up 100% of my time and care. In November 1986 Jessica saw Shands and had x-rays and blood tests and they found out she had a paraesophigeal hernia, "the nissen wrap was apart," her stomach was going up into her chest wall making her stop breathing and her heart rate slow down. She had surgery January 2, 1987 and got out of the hospital the 16th of January. In September 1986 we found out that against everything we believed I was pregnant. Due in May I was fine until I returned from Shands W/Jessica in January when I started having complications I was confined to bed then only going out to take Jessica to Easter Seals, every Tuesday morning (since August) for therapy. In March 1987 I was hospitalized for 2 weeks at Fish Memorial for 3 days and transported to Orlando Regional Medical Center for premature labor. I came home on medication for labor which lasts 4 to 5 days and costs $90.00 each time I get it. We have tried every Government and Private Agency (except going on the 6:00 news) and get the same answer your husband makes 20.00 a month to much. He brings home 180.00 a week and our bills are $800.00 a month just for vehicle pmt, housepmt, Insurance, lights and telephone. If it weren't for overtime we wouldn't pay those there must be something someone can do to help us before we lose the house in May. We are 3 months behind and they are starting foreclosure soon.

LORRAINE WHITEHORN.

Name: Roberta Wickley, Ray Olsen.
Address: 5824 Westport Drive, Port Orange, FL 32019.
Telephone: (904) 767-0237.
The testimony written below represents:
1. Personal experience in my family: Yes.
2. Work related experience: No.
3. Research/Other: No.

In December of 1984, my husband and I had our third child. He was born prematurely by 13½ weeks and weighed 2 lbs. 6 oz. He is now 28 months and functions at age level in his gross motor and fine motor skills. His speech and language development is severely delayed and he tests at a 14-month level, although his cognitive level is behind only a few months. He has had three major surgenes at Shands Hospital after his 3 month neo-natal stay at Halifax Hospital. He has been attending the Easter Seals Program since he was 10 months old.

Our main concerns were two: 1.) to enroll him in a program such as early intervention as soon as possible (we waited 5 months); and 2.) to have medical care adequately available for premature infants. We were very happy with our experience at Shands, but needed to be referred there.

It is so difficult to educate the public before the problem and probably not a necessity. More important is educating health-care professionals to be alert to the many and endless problems these babies have.

Our third child made my husband and myself firm believers in miracles. But he also alerted us to the importancy of child advocates. Not many knew what to expect with him, and frankly, professional advice was not always in his best interest.

Currently we are seeking information on speech development, which is not easy. We are relying on our best interests in him. He will probably be dropped from Easter Seals in September and will have to see a speech therapist on an out-patient basis, if we can afford that.

ROBERTA WICKLEY.

Name: Jacquelynn A. Williams.
Address: 2133 Van Lake Dr., Englewood, FL.
Telephone: (813) 474-5665.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

I am the stepmother of an 11 year old boy with many handicaps. His mother left him, alone with his brother and sister, at age 6. I think she, being young herself, was overwhelmed with the difficulties of caring for a child like Christian and, with counseling and support, felt the only way out was to leave. Here are the problems now: living in Englewood we are a two county town and much time is wasted by agencies fighting back and forth as to who is responsible, Charlotte or Sarasota County, to provide services for Chris. I waited, continuing to call and write, 2½ years for a parent trainer to help me learn how to deal and help my family deal with Chris. Because he did not get help early in life, nor did his mother, he developed many "behaviors", that are making family life very stressful and will take years to "unlearn"; meanwhile, we deal with finding and being able to afford medical help. My husband makes enough money to provide our needs but not enough for even the blood test needed every three months for Dialintin level checks, EEG's to monitor and record, regular visits to the doctor for just maintenance. So, we get what we can afford to get for him, when we can afford it and I live with the guilt of not providing everything I've been told by doctors to do for Chris because of *money*. Chris is not healthy and I lack confidence that he's o.k. etc . . . because of this problem of money! You understand that we are not poor, we are middle class, paying our own way bit by bit and I do not expect or want handouts but I do need help and cannot get it.

There are many more problems I could discuss here, but for now, I would stand on a mountain top and rejoice if this one problem could be solved.

Thank you,

JACQUELYNN A. WILLIAMS.

Name: Susan M. Wilson, RN.
Address: 6412 Crystal Brook Drive, Tampa, FL 33625.
Telephone: (813) 963-2348.
The testimony written below represents:
1. Personal experience in my family: no.
2. Work related experience: yes.
3. Research/Other: no.

I am a Registered Nurse, working in the Neonatal Intensive Care and Child Development fields for almost 10 years. As part of the Regional Perinatal Intensive Care program funded by the state, I have worked with a vast number of infants and children who have handicaps that were neither preventable or reduceable, given availability of appropriate services. I have seen the whole spectrum of the problem. It starts with young and/or indigent mothers, lacking support both emotionally and financially, who do not receive prenatal care. These women present to the hospital in active, unavoidable labor, delivering 1-3 pound babies who will require months of hospitalization and services. These same women will have trouble attaching to their sick infants, either due to lack of understanding, or lack of support services like transportation to the hospital or money to prepare for the child's homecoming. When these small, sick infants are finally ready for discharge, the mothers are unable to arrange for appropriate living conditions, primary pediatric care, or clothing and toys for their infants. It is very difficult, for example, to keep a baby healthy in the winter when you cannot afford to heat your home! Public Health Departments here will give babies shots, but won't see sick children! I currently work in child development, assisting with the Developmental Evaluation component of the RPICC program funded by the state. We constantly see children whose mothers cannot obtain the basic primary pediatric care they need due to lack of money. Few pediatricians here accept Medicaid. Then there are the handicapped children who would profit tremendously from easy availability of such services as Occupational and Physical Therapy, hearing screening, speech and language screening, and speech therapy. Children who need these services and have no money either never receive them and suffer lifelong, or must wait months and years for them. Every child has a right to optimal medical care!

SUSAN M. WILSON, RN.

Name: Karen S. Woolley.
Address: 5390 Houdan Ave., Naples, FL 33962.
Telephone: (813) 261-7678.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: no.

As the mother of a son with learning disability and a daughter with a hearing disability, I know only too well of the need to have help dealing with the out-rageons financial bills that go along with these problems. Insurances don't cover any degree of any of these disabilities. And they should cover some part of it! After all isn't that why we buy the insurance? Someone has to help these children and the children of the future.

KAREN S. WOOLEY.

Name: Mary Ann Yau.
Address: 119 Mitchell Drive, Brandon, FL 33511.
Telephone: (813) 685-5782.
The testimony written below represents:
1. Personal experience in my family: yes.
2. Work related experience: no.
3. Research/Other: yes.

My fourth son, Benjamin, has Down's Syndrome, is enrolled in public school's EELP (Early Exceptional Learning Program) for ages 3-5.

Ben, at 44 mos, functions at 24± age. He is most delayed in speech (12-15 mos.) Because of criteria for eligibility, Ben is denied speech therapy (and all therapies) in Hillsbourgh County. He is not functioning in speech as for below his functioning age as is necessary to gain services.

As he grows, this disparity will be more glaring. The crucial years of learning are now for Ben. There are good money allotments for sports, drama, etc. but not for speech therapy, etc.

MARY ANN YAU.

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